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Author(s): Gail Christina Ashton

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A child's death:

A heuristic exploration of mothers' grief

Gail Christina Ashton

Dissertation submitted to the University of Liverpool for the Degree of Master of Arts
(Counselling Studies) in part fulfilment of the Modular Programme in Counselling
Studies.

November 2006

Declaration

This work is original and has not been submitted previously in support of any qualification or course.

Signed _____ (

Name _____ **Gail Ashton**

Abstract

The death of a child is one of the most difficult losses that can have complicated, intense and long-lasting effects upon a bereaved parent. This qualitative heuristic study explored the grief experience of mothers after the death of their children, considering how or whether bereaved mothers' world-view was changed, how they rebuilt 'self' whilst adapting to a new and changed life and exploring the importance and value of remaining connected to and continuing the bond with their child. Post-traumatic growth was also explored in addition to any existential, spiritual or life changes that resulted during the mothers' grieving. The experience of the researcher, a bereaved mother and counsellor, remained visible within the research, integrating her own personal and professional experience alongside the participants' stories. Data for analysis included interview transcripts with five bereaved mothers together with rich data such as poetry, narratives and photographs. This data was analysed using an inductive approach and Moustakas's (1990) heuristic process of data analysis. The constant comparative method informed this process. The findings not only highlighted the intensity and lifelong process of grief following the death of a child, but also significant changes in world-view, perspective on life and personal values, alongside personal growth and a changed view and altered level of understanding and valuing of people. Significant changes in self and attitudes were described such as a new enthusiasm for living, pride in self, contentment, strength, confidence and a new sense of enrichment, joy and pleasure, alongside the continuing pain of loss and an ongoing relationship with the child. The ways in which child death can be experienced and what can enable bereaved mothers to reconnect and rebuild their lives after such a devastating loss was additionally highlighted. The implications and findings of this study are discussed and potential further areas of study indicated.

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I would like to thank Angela, Elizabeth, Helen, Janet and Kate (these are pseudonyms for research participants) for sharing with me their children and lives with me. I know that for many it was a brave and difficult choice to take part in the research, but something that they were all very committed to doing. I hope my research does justice to their stories. To the manager of the bereavement centre for his support and encouragement.

My husband Steve and eldest son Tom, who have always been supportive of my research and my MA study. Tom began his own Psychology degree journey in September. To dad, who is quietly interested, and my sister Jackie who is always there for me.

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In memory of my youngest son Sam who died in 1995 aged five and a half, and also my mum who died suddenly whilst I was carrying out this research. My relationship with both of them is part of my everyday life, and my love for them continues.

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Introduction

Context

*Give sorrow words:
the grief that does not speak
whispers the o'er-fraught heart and bids it break*
(Shakespeare; *Macbeth*, Act 4, Scene 3)

I remember.
Sometimes with sadness,
and sometimes with a rush of pain,
and I am thinking
that this cannot be so.
Sometimes a feeling of calmness comes
that allows the memories
to wash over me
with a sense of inevitability,
and an acceptance of this reality.

I'm beginning to realise that there is no pattern or norm.
The feelings come as they will,
and often not when I expect or anticipate,
but usually in an overwhelming rush of pain
or a feeling of panic.
And then, when I think, "this should feel awful",
at the moment when I expect the pain to be at its strongest,
I am left in awe, or empty, or numb.

I can feel myself sinking.
I am exhausted.
My mind and my thoughts get confused
and I feel quite light-headed.
It is as if my head doesn't belong to my body,
I feel detached from reality.

I keep having flashbacks,
remembering him dying,
feeling as if I am there again.
The flashbacks are so frightening,
watching my child die
over and over again.

*Diary entry, 1996.
6 months after Sam's death
Gail Ashton*

Background

*And can it be, in a world so full and busy,
The loss of one weak creature makes a void in any heart,
So wide and deep that nothing but the width and depth
Of vast eternity can fill it up.*

(Charles Dickens, *Dombey and Son*, 1847)

Most researchers have acknowledged that the death of a child is one of the most difficult forms of bereavement (Worden, 1991; Bonanno & Kaltman, 1999; Silverman, Klass & Nickman, 1996; Tedeschi & Calhoun, 2004; Talbot, 2002; Knoj & Keller, 2002; Riches & Dawson, 1996) and “can be one of life’s most devastating losses and its impact lingers for years” (Worden, 1991 p. 154). Young and Papadatou (1997, p.192) describe the complicated, intense and long-lasting effect of a child’s death on the bereaved parent, which leaves the parent looking ‘atypical’ or even ‘abnormal’ in their mourning, when in fact they are not.

Often parents’ view of the “world” and all of their assumptions and beliefs about safety, security, predictability and trust are challenged and profoundly changed by the experience. Such a loss feels like a violation of the belief systems that give life meaning (Neimeyer, Prigerson & Davies, 2002) and the world is seen as a much darker and less optimistic place.

Whilst the death of a child can present the kind of suffering and challenge to self and previous world beliefs, it can also create an existential crisis; a search for the meaning of what it is to be human (Talbot, 2002; Wheeler, 2001), a search to make sense of the death and to find some important existential benefit or life lesson (Neimeyer, Prigerson & Davies, 2002).

Aims and Rationale

The purpose and focus of this study is to explore and discover the grief experience of mothers after the death of their children. The research will focus on discovering how mothers experience and express their grief, enabling a deep and broad understanding and description. In selecting mothers, I am not reflecting any hierarchy of suffering within the bereaved parent group, however, for a study of this small scale, looking at mothers and fathers would be too broad a topic. I believe that a separate study looking at the experience of fathers' grief would also be beneficial.

My research interest comes out of my own experience as a bereaved mother. After the death of my son, my experience did not seem to fit within the 'norm' of grief theory and models. I experienced debilitating emotional pain, which at times manifested physiologically with symptoms that further compounded the painful task of grieving and living with my loss. Grief impacted upon every aspect of my life and ability to function: socially, relationally, as a mother and as a professional. I felt as if I was stuck, abnormal and unable to move forward. I had no reference point in my life previously to enable me to make sense of this new world I was now in. In fact, the only place I felt I was 'normal', in any sense of the word, was when I was with other bereaved parents who I felt knew something of how my life was. Labeling grieving as abnormal or atypical may not be helpful to the bereaved parent and "grieving parents might judge themselves for failing to conform to mythical but commonly held norms" (Murphy, Clark Johnson & Lohan, 2003).

I used writing and creativity to help me express my loss: writing a journal, life drawing, learning to play the piano, talking openly about both of my sons' lives, one living and one dead. I stayed connected with Sam through his favourite 'objects' and representational images such as sunflowers. I became aware that such creative means were enabling me to continue my bond with him and also nourishing me in my new life without him.

In my work as a counsellor I have found that many bereaved clients experience what would be considered to be complex grief reactions. The DSM 1V (APA 1994) refer to Bereavement as the diagnosis when the symptoms of the grieving process are a reason for clinical attention. The DSM 1V also states that the sadness of grief can resemble the symptoms of a major depressive episode. However, there is no reference made to the breadth of reactions that many bereaved people describe. It has become more evident to me through my own experience, and that of clients and other bereaved parents that I have had knowledge of, that the experience of grief and the impact upon functioning does not always fit within the model of grief and what are considered to be normal patterns of grief response.

My research therefore is about enabling the participants to be able to describe how they experienced their grief after the death of their child, and what enabled them to remain connected with their child and to their new and changed life. I have tried to retain the autonomous story of each participant as a way of reflecting each discreet individual experience. This dissertation is a "shared road" (Hindmarch, 1993) between the participants and myself, all of us bereaved mothers.

This study will be helpful for professionals who support bereaved parents, and for other bereaved parents, alongside the current existing research into bereavement and parent bereavement. It may elicit a richer understanding through the stories of the mothers interviewed of the ways in which child death can be experienced and what enables bereaved mothers to reconnect and rebuild their lives after such a devastating loss. I am mindful of the fact that this study focuses on five mothers who, by the very nature of their role as bereaved parent helpers, were already directing their grief into a supportive role within a community of grief, and is not necessarily reflective of all bereaved mothers.

Researchers Perspective

Traditionally quantitative and phenomenological researchers have been required to recognise, clarify and bracket off their own biases and assumptions relating to the subject of inquiry; however heuristic research involves self-search, self dialogue, and self discovery (Moustakas, 1990). I am congruently acknowledging my place in the research from the outset, whilst being open and receptive to discovery. My challenge as a bereaved mother has been to integrate my personal experience, my professional experience as a counselling practitioner, and my role as researcher, whilst being alongside the participants.

I see the integration of these areas as a challenge and a benefit, not only to the research but also to the participants who often do not want to be ‘observed’ by an outsider. Sadly, the death of my own child gives me ‘insider’ status. Tedeschi & Calhoun (2004, xiii) reflect, that whilst they have extensive clinical and research experience, they lack the “direct and painful experiential knowledge about parental bereavement” that comes from being a bereaved parent. Therefore as a bereaved mother, I have hopefully integrated

academically sound research alongside experiential knowledge, whilst showing empathic sensitivity to the participants and the subject I have chosen to explore.

The research is based upon my journey alongside mothers who have described and explored their experience of grief, after the death of their child. As researcher I have joined these women as they describe their search for meaning and understanding and hopefully the research will reflect another perspective (than generalisations of grief theory), to the depth of experience that is child loss. The narrative of the participants, their unique language and expression of their loss, may convey how bereaved mothers experience their life after the death of their child.

It is my belief that it is the bereaved parent who is the expert in his or her own unique experience of loss, just as Rogers' (1961) Person-Centred therapy involves the therapist's entry into the client's unique phenomenological world. Parental bereavement is a unique form of loss, a deep underlying sadness and lifelong process of grieving is experienced (Klass, 1998, 1999; Tonkin, 1998; Talbot, 2002; Tedeschi & Calhoun, 2004; Geron, Ginsburg & Solomon, 2003), and it has no particular pattern or model which can accurately express the journey which many bereaved parents find themselves on.

Literature Review

"There is no one way to survive the death of a child, no proven method of processing grief that ensures the best possible accommodation to this traumatic loss."

(Talbot, 2002, p 3)

Author, researcher and bereaved mother.

Introduction, Intent and Search Strategy

The literature review focused on books, journal articles and electronic databases. There are an abundance of books, which examine grief models and grief experience, but there are fewer that explore specifically the experience of bereaved parents and child loss.

My particular focus was on the more current research into grief which acknowledges that the bereaved remain involved and connected to the deceased and find their own unique way of continuing their relationship with the person who has died (Silverman & Klass, 1996; Klass, 1999), and that a changed, but enduring attachment to a child who has died is indeed common and enabling for bereaved parents (Tedeschi & Calhoun, 2004).

I have looked at the ways in which bereaved mothers continue the process of integrating the loss within their lives and moving forwards (Tonkin, 1996; Talbot, 2002), whilst also preserving continuity with who they were, who they are now as a result of their loss, and their now changed world (Neimeyer, Prigerson & Davies, 2002).

Many bereaved parents present with what is described as complex reactions and traumatic grief. These labels are often applied to the intensity of the grief reaction in bereaved parents and it is questioned if this is indeed the norm for this group (Kaltman, 2003; Murphy, 2003; Keesee, 2001; Simpson, 1997; Davies, 2001).

I have made reference to how parents communicate their grief (Kamm & Vandenberg 2001), experience the memories (Hentz 2002) and find meaning in their experience (Neimeyer, 2002). It is now well recognised how grief can severely impact upon the bereaved parent’s well-being (Znoj & Keller 2002; Olsen 2003/4).

Literature was found via journals and electronic databases including: ASSIA, PsychINFO, PubMed, and in a wide range of journals from Counselling, Psychology, Nursing, Death Studies and Sciences.

Using the following combination of search terms enabled me to find articles in the field of bereavement or grief reaction and child death:

• Counselling and mothers and grief or loss
• Child death and mothers and grief or loss
• Child death and parents and grief or loss
• Bereaved parents and grief
• Grief and narrative research
• Child death and grief and growth
• Child death and bereavement

Books and journal articles have formed the basis of my literature review. Also included is research accessed through the direct contact I have made with leading international grief theorists and researchers via the Internet and email, and this has proved to be a very effective way to collect articles, have discussion and network with other researchers. They are acknowledged in my thanks for their support and encouragement.

After analysing the articles, I extrapolated the following headings:

1. Grief theory/models
2. Parents' experience of grief
3. Mothers' experience of grief
4. Impact of grief on relationships
5. Trauma, grief and wellbeing
6. Grief expression; narrative, poetry and art
7. Finding meaning
8. Existential and Spiritual
9. Continuing The Bond

Grief theory/models

*Give sorrow words: the grief that does not speak
Whispers the o'er fraught heart and bids it break.*
(Shakespeare, *Macbeth*, 1603-1606)

Death is one of the unchangeable facts of life, at the basis of our existence as human beings. Yet however prepared we feel we are for that reality, little in fact prepares us for the experience of death, and our human struggle with it is not new. Literature, art, music and performance are inspired by love, loss and the experience of grief and suffering.

*Grief is like a bomber circling round and dropping its bombs each time
the circle brings it overhead.*
(C.S.Lewis, *A Grief Observed*, 1966, p36).

Grief theory has come out of the systematic attempt to understand the grieving process and the various stages which the mourner journeys through. These general theories can provide guidance to practitioners and researchers who wish to understand the reactions of the bereaved. Theoretical models are based on research and general findings, and whilst they can offer a helpful framework for those supporting the bereaved, they can also feel confining, prescriptive and restricting. Such understanding needs to be balanced alongside the unique experiences of the bereaved. Whilst there are certain patterns in grief that are recognized theoretically, every individual has a unique and individual response.

In the last century bereavement theorists assumed that recovery from loss requires a period of grief work in which the goal is for the mourner to disengage from the attachment formed with the deceased. This involved “working through” a series of stages, phases and tasks, which would eventually enable the bereaved to adapt or return to a pre-loss status (Freud, 1961; Wortman & Silver, 1989; Kubler-Ross, 1973; Worden, 1991; Parkes, 1986; Bowlby, 1980). A more recent advance in our understanding of

grief work is the dual process model developed by Stroebe and Schut (1999). They suggest that avoidance of grief may be both helpful and detrimental, viewing grieving as a dynamic process in which there is an alternation between focussing on the loss of the person who has died and avoiding that focus. Both the loss orientation and the restoration orientation may be needed at different times to adjust and manage life alongside the loss.

Rando (1995) acknowledged that the stages are not purely sequential and theories need to be used as guides allowing for individual expression. Stroebe (1992) suggests that the notion of “normal grief”, and the categorising of certain responses as pathological, is not supported by research evidence. These widely accepted beliefs about coping with loss, including the assumptions that working through grief is necessary to achieve detachment and that most people recover from and fully resolve the loss are challenged by current theory (Nonanno & Kaltman, 1999; Klass, 1998, 1999; Riches, 2002; Talbot, 2002; Tedeschi & Calhoun, 2004).

The post-modern, and in some respects existential, approach to understanding grief does not impose universal assumptions upon the experience of bereaved people (Madison, 2005). Recent theorists and researchers have moved away from the traditional models of mourning. A new theory of grief is emerging, which challenges the previous assumptions that the bereaved need to “let go”, and indeed encourages the maintenance of continued symbolic bonds with the deceased, with the emphasis on negotiating and renegotiating the meaning of the loss over time and integrating the memory of the deceased into their ongoing lives (Klass, Silverman, & Nickman, 1996; Walter, 1996; Bonanno & Kaltman, 1999; Neimeyer, 1999; Tedeschi & Calhoun, 2004; Talbot, 2002). Klass (1999) found in his research with bereaved parents in a self-help group that

maintaining the bond with the child who had died was part of healthy adjustment, where in the past this may have been considered pathological. However, grief responses are on a continuum and there may also be times when the attachment and continuing bond with the dead child could be indicative of pathology and an inability to function well.

The dual process model proposes needing perhaps to take time off from grief in order to maintain life and functioning, alongside the task of grieving, which may include the notion of continuing the bond throughout life. As such the research is waiting to be done on people who sever bonds completely and whether in fact that is supportive and indeed necessary for some, and in particular circumstances (Klass, 2006).

Whilst death is permanent and cannot be changed, the process is not. The resolution of grief is linked to what it is to be human and tied to the meaning of our bonds with significant people in our lives, to our membership with family and community and to wider social meanings and life context. We should not assume that one's own culture or experience forms a baseline for understanding others response to grief (Rosenblatt, in Stroebe, Stroebe & Hansson. 1993). Grief is experienced uniquely and expressed in a substantial range of responses and in relation to a wider social and cultural context.

Parents' experience of grief

Journal of Child Psychology and Psychiatry

(Kathe Kollwitz "Mourning Parents" 1920)

It is widely acknowledged by researchers and clinicians that the most difficult and painful bereavement is a parent's loss of a child (Tedeschi & Calhoun, 2004; Geron, Ginsburg & Solomon, 2003). In society today the death of a child is statistically rare and conflicts with our life-cycle expectations, and we are therefore not prepared when it occurs (Parkes, 1987; Jiong, Johansen, Hansen & Olsen, 2002). It contradicts the perceived natural order of life and death and symbolises the dying of one's hopes and most precious goals, demanding a strong and often conscious individual coping effort (Znoj & Keller, 2002). Such a loss violates and shatters the bereaved parent's assumptive world producing intense turmoil (Wass & Neimeyer, 1995; Wheeler, 2001), forcing them to re-examine their worldview, to reaffirm or modify their basic understandings about themselves and the orderliness of the world. With this comes a sense of unjustness and unfairness, which challenges the basis of their previous held beliefs and assumptions. Life becomes vulnerable and sometimes a de-emphasis on worldly values occurs (Knapp, 1987), and previous held values and beliefs are remodelled and often replaced. Parents move from the equilibria in their inner and social worlds before a death, to a new equilibria after a death (Klass (1999).

The parent attachment bond to children is not only a powerful biological drive that ensures the continuation of life, but also a psychological and social drive, which operates for the production and caring of children (Bowlby, 1969, 1973). It is also understood that the grief experience of each parent may differ, due to the varied and particular relationship they had with their child (Worden, 2003). Whilst relationships between parent and child can be on a continuum from ambivalent to strong and loving attachments, recent thinking suggests that when a child dies the parent has the difficult task of transforming the bond in a way that enables the child to remain a continuing reality in their lives (Klass, 1999). The kinship and relationship with the deceased is a significant factor in the grief experience. The findings of a study by Ginzburg, Geron and Solomon (2002) revealed that bereaved parents are more prone to difficulties following the loss of an adult child.

The context in which the loss occurs must be considered if we are to understand the responses experienced (Bonanno & Kaltman, 1999). Often the grief of bereaved parents can appear more complicated, intense and long lasting compared to other losses. They may experience physiological symptoms of panic, such as shortness of breath, tachycardia, dry mouth, sweating, frequent urination, digestive disturbance and choking sensations (Rando, 1995). The dividing lines between ongoing grief and mourning as “normative” as opposed to “maladaptive or pathological” are difficult to draw (Rubin, 1993). In the past, if a person’s narrative conflicted with the “normal” stage model of grief they were treated as somehow “disordered” (Levine, 1996, cited in Gilbert 2002). Therefore grieving parents seem “atypical” or even “abnormal” (Parkes, Laungani &

Young, 1997) and often judge themselves for failing to conform to these mythical but commonly held norms (Murphy, Clark Johnson & Lohan, 2003).

*There is no one way to survive the death of a child,
No proven method of processing grief that ensures
the best possible accommodation to this traumatic loss.*

(Talbot, 2002, p3)

Society generally has unrealistic expectations that parents should “accept” their child’s death and “get over it” or “let go”. But, the parent does not “get over” the death of a child, because a part of the future has died (Klass, 1998). Many parents feel ashamed that they haven’t dealt with their grief better, and this creates a sense of inadequacy and failure and compounds their grief (Tonkin, 1998). Contemporary culture does not easily include the idea of irreparable loss (Klass, 1999), but in fact parental bereavement is a permanent condition and can mean being in a perpetual state of chronic mourning many years after the child’s death and always in conscious awareness (Klass, 1999; Talbot, 2002; Tedeschi & Calhoun, 2004). The unique and intense reactions displayed by bereaved parents are not abnormal or bizarre, but in fact similar to those experienced by many other bereaved parents (Knapp, 1987).

For bereaved parents talking and open discussion about their child and child’s death enables an expression of their loss and grief (Knapp, 1987). The benefits of joining a bereaved parents’ group can include identification, empathy and a sense of belonging, and feelings and responses may be legitimised and normalised within such a context (Geron, Ginzburg & Solomon, 2003; Klass, 1997).

Silverman (1996, p. 197) states that in healthy resolution of grief, “the relationship to the deceased remains fluid and coexists as an adjunct to ongoing interactions in the parents’

daily life”. Bereaved parents integrate their child into various parts of self and also the social systems within which they function in a variety of ways (Klass, 1997). Parenting is a permanent change to the individual and parental bereavement is also a permanent condition, for the death of a child is part of the self (Klass, 1998). Bereaved parents may find solace, meaning and resolution in the development of self through new social interactions and interests. They may learn to live in the new world, forever changed and altered by the death of their child.

3. Mothers' experience of grief

*As long as I kept moving, my grief streamed out behind me like a swimmer's long hair in water.
I knew the weight was there, but it didn't touch me.
Only when I stopped did the slick, dark stuff of it come floating around my face,
Catching my arms and throat till I began to drown. So, I didn't stop.
The substance of grief is not imaginary. It's as real as rope or the absence of air.*

(Kingslover, *The Poisonwood Bible*, 1999)

A child's death creates a crisis of meaning for many parents, especially mothers (Riches, 2002). The identity and role of the mother will be severely impacted upon and in some cases completely destroyed, and her view of the world before, during and after the death is greatly altered. This changed and altered world view is related to the meaning that a mother gives to the experience – a meaning that is temporal, connected to people and bound in the context of experience in the mother's world (Lauterbach, 1994).

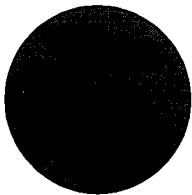
Among those who have experienced the loss of a close person, mothers were found to be the most severely affected (Clieran, 1993). Whilst mothers describe their grief as more public, fathers often describe their grief as a more private matter (Klass, 1998). Rando (1983), when studying parental bereavement following the loss of a child through cancer, found that mothers reported more intense reactions to bereavement and poorer subsequent adjustment post loss than fathers. In a study which investigated the emotional

consequences for parents following the death of their child, Znoj & Keller (2002) found that bereaved mothers reported higher depression scores and greater deterioration in physical health than fathers. Jiong, Johansen, Hansen & Olsen (2002) reported an increased mortality rate in mothers whose child had died and questioned whether this was due to negative lifestyle changes as a result of the loss. Hentz (2002) explored the experience of body memory in women after a significant loss. The findings of this research suggested that the body carries and holds all types of memories, and that by focusing on the whole person, mind and body, a more holistic understanding of grief and mourning can be enabled.

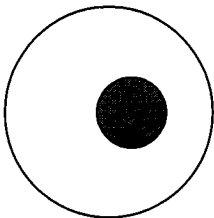
For mothers especially, survival for themselves involves a sense of hopelessness and no way of justifying their lives or continuing without the deceased child and bringing feelings of guilt and vulnerability too (Knapp, 1987). Guilt can be attached to a sense of failure at the mother's powerlessness and inability to protect their child, and in surviving and continuing when they did not. It is also common for mothers to feel a sense of loss related to their role (Tedeschi & Calhoun, 2004), with all of the tasks that caring for their child involved.

Lois Tonkin (1996, p 10) described a model of grief which was presented to her by a bereaved mother. This model reflects the fact that for many, the grief experience does not go away, and that growth can also emerge from the experience.

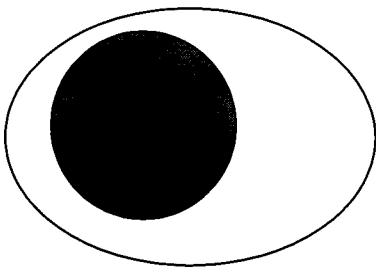
Lois Tonkin - Model of Grief and Recovery



At the time of her child's death she said, grief consumed her totally, filling every part of her life, awake and asleep. She drew a picture with a circle to represent her life and shading to indicate her grief.



She imagined that as time went by the grief would shrink and become neatly encapsulated in her life, in a small and manageable way; she was realistic enough to assume that it would not go away entirely.



But what happened was different. The grief stayed just as big, but her life grew around it. There were times, anniversaries, or moments which reminded her of her child, when the grief felt just as intense as it ever had, but increasingly she was able to experience life in the larger circle.

4. Impact of grief on relationships

Each person's response to loss is the unique product of their own individual experience.

(Lendrum & Syme, 1992)

The effects of a child's death on marital and family relationships, wider social relationships and the individual's view of the world are profound. The loss and trauma experienced changes the individual; their identity may be extinguished or badly damaged and the nature of their relationships changed as well (Riches, 2002). Often the burden of a child's death can add to underlying marital problems and the differing grief patterns in each partner can also present tensions in the relationship (Klass, 1998). In a study of bereaved parents 4 to 60 months after their children's death (Murphy, Clark Johnson & Lohan, 2003) parents reported deterioration in their marital satisfaction with implications for communication problems, potential separation and divorce, and parenting of other children. Rubin (1993) found that whilst some couples relationships founder under the stress others protect and assist the bereaved.

The greater the discrepancy over issues such as the child's belongings, the greater the potential for misunderstandings, whilst the sharing of meanings enables a greater sense of the experience and higher levels of comfort and growth (Neimeyer et al. 2002). The death of a child can have a paradoxical effect on the relationship; the shared loss of a child by the parents can create a profound bond and connection between them, and at the same time can create tension and estrangement as each individual struggles to make sense of their unique grief experience. Given that a child's death will challenge the world view, social, spiritual and existential beliefs of bereaved parents, then it is not surprising that relationships are also questioned and challenged (Klass, 1998).

5. Trauma, complex grief and physiology

Many grief theorists have used the terms *complicated grief*, *exaggerated grief*, *masked grief* or *pathological grief* as terms which describe symptoms or behaviour that doesn't fit within what is seen as the normal grieving process. However, the uniqueness of the parent/child attachment and the subsequent experience of grief, which follows after the death of a child (Klass & Marwit, 1989), can mean that bereaved parents have the potential to experience and exhibit symptoms characteristic of intense, abnormal or complicated grief. This is consistent with Kamm & Vandenberg's study (2001) into grief communication, reactions and marital satisfaction in bereaved parents which found that rather than being regarded as pathological, this pattern seems to be the norm for bereaved parents (Davies, 2001). Znoj & Keller (2002) found that bereaved parents had increased signs of post-traumatic stress reactions, elevated depression scores, and a minority indicated being physically unhealthy.

Grief is on a continuum of reaction and individual response, however bereaved parents may present with more intense reactions, and for longer. In the past anyone whose grieving process conflicted with the "normal" stage of grief was treated as somehow "disordered" (Levine, 1996). This assumption is unhelpful to bereaved parents. Bonanno and Kaltman (2001) reviewed empirical evidence on diagnostic relevance of grief reactions and questioned what constitutes normal or common grief, and when, if at all, too much or too little grief might be considered abnormal or even pathological.

The relationship between grief and trauma / post-traumatic stress disorder and the intersection between these areas has only recently begun to be explored enabling

understanding of these more complex areas of the process of grieving (Kaltman, 2003; Bonanno & Kaltman, 1999; Rando, 1997; Simpson, 1997).

Murphy & Clark Johnson (2003) examined post-traumatic stress disorder in parents following the violent death of a child and have carried out various studies in this area. They found that mothers had significantly higher levels of PTSD than fathers. Keesee (2001) looked at the predictors of normal and traumatic grief for parents who had experienced the death of a child. Johnson (1993, p.482) saw PTSD and grief reactions as “inextricably intertwined strands which were inseparable”. More serious study is needed into the relevance of the relationship between grief and PTSD (Simpson, 1997).

The death of a child is one of the most extreme stressors and can have both short and long-term effects on parents’ health (Rubin, 2001). The psychological stress induced by the death of a child could affect health outcomes in several ways: susceptibility to disease and development of cancer and diseases of the cardiovascular systems. Stress can also affect lifestyle, such as alcohol consumption, smoking and dietary patterns, which could also impact on health and mortality (Jiong et al, 2002; Jiong et al, 2003).

6. Grief expression: narrative, poetry and art

Essentially our lives are stories. Story telling is integral to research and therefore the means of telling that story by the participants is essential. The researcher is collaborator and editor.

Grief can be expressed in many ways and in counselling and psychotherapy practitioners can enable their clients to express their experience in language, drawing and narrative.

Many bereaved parents write journals, poetry and narrative as a way of expressing the intensity of their loss and sadness. Writing can be a powerful means of articulating and addressing loss and processing the traumatic and painful memories in a releasing way and can “crystallise a moment, validate an emotion, or convey a felt sense” (Neimeyer, 1999, p. 68). Narratives are representational of a lived experience and are subject to change and reinterpretation. They are like a continually evolving sketchbook of memories and life experiences (Gilbert, 2002). The process of telling one’s story can contribute to an altered understanding of that story for the teller (Riches & Dawson, 1996), or for a clarification, means of expression and self-understanding in what is often very hard to articulate and verbalise. It can offer a perspective on the experience and a sense of what it meant that may not have been seen or known before (Ellis & Bochner, 1992).

Human experience can also be expressed and depicted through art and sculpture. Kathe Kollwitz struggled with the last chapter of her son’s life (he died in 1914 during the first world war). Her struggle inspired her to express her feelings in artistic form, through drawings and sculpture.

Woman with a dead child 1903
“Drawing is the only thing that makes my life bearable.” *Kathe Kollwitz*

Many artists have depicted the grief and suffering of bereaved mothers and tried to represent the intensity of grief:



Bereaved Mother Mourning After the Massacre of the Innocents 1771 – 1774
Johann Heinrich Fuseli,



The War 1943
Marc Chagall

Depicts a bereaved mother covering her face with her hands in the bottom left hand corner of the painting.



Grieving Mother

Sculpture by Anna Vafia



Grieving Mother 1991

Joseph Turkaly

7. Finding meaning - Growth

*Last night, walking that long way home through the rain, with the blister on my foot,
I still made a short detour to seek out the flower stall, and went home with a large bunch of roses.
They are just as real as the misery I witness every day.*

(Etty Hillesum, *An Interrupted Life: The Diaries and Letters of Etty Hillesum 1941-43*, 1999)

The experience of the death of a child may spur parents to experience their lives in sharp new ways, which bring to them new levels of meaning. For others, loss wounds the ability to negotiate and live life adequately (Rubin, 1993). The death of a child has been conceptualised as a crisis of meaning (Wheeler, 2001; Talbot, 2002). The subsequent search for meaning, which happens as a result of this crisis, is an important aspect of grief and coping with the death of a child. A turning point in the bereavement process occurs when the parent identifies a reason, passion or focus in their new life (Kagan, 1998).

Human beings seek to find meaning in mourning, through the struggle to construct a coherent account that preserves a sense of continuity with who they have been, and also by integrating the reality of a changed world into their conception of who they must be now (Neimeyer, Prigerson & Davies, 2002). Many parents describe the struggle to maintain who they were before the death of their child, and integrate this within a new self who can continue and find meaning in their life in the here, now and future. In a study looking at the search for meaning in parental bereavement Wheeler (2001) found that some parents found meaning through keeping the memory of their child alive and through a renewed appreciation of their connections with people and personal growth.

Therefore, the death of a child requires complex reorganisations of the social self and of the private and intrapsychic structures, and the resolution of this disequilibrium is the establishment of a new self within a changed world (Klass, 1998). Part of the resolution

of grief is in moving from the intense experience of the pain of such a loss, to making the child's life and death meaningful within their own. "In making their own life meaningful, the inner representation of the child is made real" (Klass, 1997, p. 161). Some bereaved parents can completely transform their way of thinking and being, and this can result in the reordering of life's priorities, enabling a greater appreciation for each day and relationships (Murphy & Clark Johnson, 2003). Therefore the search for meaning can lead to existential and spiritual growth for many.

8. Existential and Spiritual

The death of a child presents the kind of suffering and challenge to self that creates an existential crisis – a search for the meaning of human existence.

(Talbot, 2002, p. 2).

Until recently positive experiences were thought to be rare in bereavement. However recent studies have demonstrated that positive cognitive and emotional experiences associated with bereavement are far from infrequent (Bonanno & Katman, 1999). Post-traumatic growth is now being well documented (Linley & Joseph 2002, Neimeyer 2004), and can arise after a period of rumination and restructuring following the trauma (Calhoun & Tedeschi, 1998, 2002). Bereaved parents can often live their lives more deliberately, deeply and fully (Klass, 1999).

Even in the most painful of losses, such as the death of a child, the search for significance is central to readjustment and many experience the enhancement of personal meaning and a deeper spirituality, rather than its decimation. Indeed the bereavement and personal tragedy can be seen as both an impediment and spur to human growth and development (Neimeyer et al. 2002; Yalom, 1980).

The death of someone significant is a powerful reminder of our own impotence, vulnerable openness and personal mortality. Whilst it is a painful and overwhelming experience, which can rip through the fabric of our assumptive world, it can also be an opportunity to explore existential realities (Madison, 2005). New models of grief are highlighting the increased appreciation of the possibility of life-enhancing spirituality and “post-traumatic growth” that often follows in the wake of great adversity (Neimeyer, 1999, 2003).

The search for meaning, reasons and justification after the death of a child can lead bereaved parents into questioning cognitively and existentially the purpose and reason of such a death and loss (Wheeler, 2001). A belief in life after death offers the hope of seeing their child again and such an afterlife is thought of as a place of an existential nature where reuniting can take place (Knapp, 1987). Many bereaved parents have conversations with religion, spirituality and explore new concepts. Valuing the spiritual above the materialistic and finding new religious-spiritual beliefs are some of the changes that can arise out of such a profound loss (Wheeler, 2001).

Sometimes the entire belief system that gives meaning to a bereaved parent can feel violated. A darker view of the universe and awareness of life’s darker side can result in pain, soul searching and also growth and realisation (Neimeyer, Prigerson & Davies, 2002). Survivors’ ability to make sense of the death and fit it into some sort of recognisable context, and to find some important existential benefit or life lesson in the loss are among the best predictors of their eventual adaptation (Davis, Nolen-Hoeksema, & Larson, 1998; Knapp, 1987).

10. Continuing the Bond

*DEATH is nothing at all. I have only slipped away into the next room.
I am I, and you are you. Whatever we were to each other, that we still are.
Call me by my old name, speak to me in the easy way which you always used.
Put no difference in your tone, wear no forced air of solemnity or sorrow.
Laugh as we always laughed at the little jokes we enjoyed together. Play, smile, think of me, pray for me.
Let my name be ever the household word that it always was,
let it be spoken without effort, without the trace of a shadow on it.
Life means all that it ever meant. It is the same as it ever was; there is unbroken continuity.
Why should I be out of mind because I am out of sight? I am waiting for you, for an interval,
somewhere very near, just round the corner. All is well.*

(Henry Scott Holland, 1847-1918)
Canon of St Paul's Cathedral

Some bereaved parents will often reflect that they cannot and indeed will not “let go” of their dead child. Indeed it has been society’s expectation that this is part of a healthy grieving process and not the individual’s choice to do so. Bereaved parents may need to develop and learn to live with a continuing bond with a dead child. For some this is not only valuable but may also be necessary to enable an anchor for the bereaved parent to move forward. These findings are consistent with Klass’s (1999) research with a group of bereaved parents.

*And within their pain and bond their lives took on new meanings,
not in spite of sorrow, but within it.*

(Klass, 1999, p8).

The literal or metaphorical sense of the continued presence of the child, or of the parent’s continued psychological connection to the child, is a common theme in the experience of grieving parents (Tedeschi & Calhoun, 2004). The representation of the child in the inner world of the parent (Wass & Neimeyer, 1995) enables the parent to connect with the past and the future and make sense of their existence within society as a bereaved parent.

Bereaved parents need to make sense of their child’s life and death, whilst integrating their child in the here and now, and yet somehow still connected in a meaningful and

helpful way. This active involvement in “writing the last chapter” and sharing the biography of the deceased person (Walter, 1999) is fundamental to bereaved parents, to enable them to make sense of how the child’s life ended. Often parents will need to make sense of the how, why and where of their child’s death.

Parents often find solace in linking objects that evoke the presence of their child (Hass & Neimeyer, 1995; Wheeler, 2001). Connection with the dead child through the integration of a cherished and tangible object, can enable parents to link the past reality of the child’s presence with the present and future reality of their absence, thus enabling them to adjust to the new and painful reality. This is particularly important for mothers who often have the tactile and nurturing role with their children.

The concept of “continuing bonds” (Klass, Silverman and Nickman, 1996) challenges the traditional thanatological approach that promotes “breaking the bonds” as a major task for the bereaved. Many bereaved parents remain involved with their relationship with the child who has died and interact with his or her inner representation as part of their ongoing life. In this process, a new self/identity emerges which has incorporated and internalised aspects of the deceased child (Kagan, 1998). This process plays an important, and positive, role in parental grief and should not be seen as abnormal, complicated or indicative of pathological grieving (Ginsburg, Geron & Solomon, 2002; Klass, 1997; Wheeler, 1999).

A child is so closely connected to a parent’s hopes, dreams, needs and wishes (Rando, 1986) and their life and death need to be acknowledged and carried into the future. Keeping the memories of the child alive may be a way to continue the child’s story and enable the bereaved parent to integrate that story into their continuing life (Wheeler,

2001). Walter (1996) also reflects upon the need to talk to others who knew the person who had died, and giving self and others permission to “retain” the dead person in their lives.

The end of grief is not severing the bond with a dead child, but integrating the child into the parent's life in a different way than when the child was alive.

When someone dies, we stop seeing and touching them with our bodies, and our conversations with the person no longer include her or his objective otherness. But the person is still a part of us, and our conversations with the person continue.

(Klass, 1999, p.39)

Conclusions

*What they remembered of him, was all that they had;
and their exquisite delineation of his character –
painstakingly ornamented over a number of years –
was their greatest masterpiece.*

(Tartt , *The Little Friend*, 2002)

Whilst there is much research on bereavement in general and some research on bereaved parents, there is little on the experience of bereaved mothers. Research into how parents continue the bond with their dead child and how they will link objects as a way of continuing that relationship is relatively new (Klass, 1999; Talbot, 2002; Tedeschi & Calhoun, 2004; Wheeler, 2001; Hass & Neimeyer, 1995). I have found no research into the use of creativity as a means of expressing grief experience and of enabling growth. Anderson, Marwitt, Vandenberg & Chibnall (2005) examined the psychological and religious coping strategies of bereaved mothers. Post-traumatic growth after trauma and bereavement has been studied more recently (Linley and Joseph, 2002; Tedeschi & Calhoun, 1998, 2004), and similarly the “perception of benefit resulting from the loss of a child” (Polatinsky & Esprey, 2000). However, research focusing on the grief experience of bereaved parents, particularly related to growth, creativity and coping strategies is limited.

Methodology

Research Philosophy and Design

*The internal search to discover, with an encompassing puzzlement,
a passionate desire to know, a devotion and commitment to pursue a question
that is strongly connected to one's own identity and selfhood.*

(Moustakas, 1990, p.175)

Positivism and phenomenology are the two overarching perspectives that shape our understanding of research (Maykut & Morehouse, 1994). Positivism relies on explanation, prediction and proof, whereas phenomenology focuses on understanding the meaning events have for the persons being studied. Qualitative phenomenological research places emphasis on understanding through looking closely at people's words, actions and records against the traditional quantitative approach, which quantifies the results of these observations (Maykut & Morehouse, 1994). Qualitative researchers believe there is not one single way of knowing and a more diverse approach to research is needed. Otherwise, as Bond (2002, p.135) reflects, "All too easily, rich accounts full of feelings, human relationships and personal backgrounds are transformed into impersonal conceptual frameworks in which thinking is privileged over action and emotion."

Human experience is expressed in many ways: spoken word, narrative, poetry, art and other expressive and creative ways as a means to articulate and internalise experience. Consideration therefore needs to be given to the way in which research is conducted. If we research human experience, ethical consideration needs to be given to whether it is appropriate to fragment the individual's story. It could be argued that researchers have a responsibility to remain close to the stories and experience of their participants (Gilbert 2002). Therefore, if the explanation of this experience is to be trustworthy (Maykut &

Morehouse, 1994) the method I chose as researcher needed to maintain and reflect that complexity. The positivist approach did not feel appropriate to conduct a piece of research into what is a highly complex and individual human experience: the death of a child.

“ The very aims of traditional science, centring on the prediction and control of events, are seen as philosophically and politically inappropriate when applied to the study of human action, which can be regarded as intentional and reflexive” (McLeod, 2003 p.7).

The overarching phenomenological approach to knowing has more of an affinity with counselling and psychotherapy, and qualitative inquiry requires the researcher to engage in a search for meaning and understanding in relation to the topic of inquiry. This is achieved by setting aside assumptions and biases and building up a thorough description of the object of inquiry. Qualitative research requires mindfulness, meditation and indwelling so that essential features reveal themselves (McLeod, 2001).

Human Inquiry (Reason & Rowan, 1981; Rowan, 1994) and the heuristic approach (Moustakas, 1990, 1994) are the two research approaches which feel closer to the practice of counselling (West, 1998) and which are at the end of the qualitative continuum. Reason (1994) refers to “critical subjectivity”; an acceptance of the researcher’s involvement with participants and an involvement that is “critical, self-aware, discriminating and informed” (Reason, 1994, p.11). The qualitative heuristic methodology felt more sympathetic to the subject of inquiry, to my own world-view and to the person-centred philosophy that underpins my counselling practice.

Traditional research methods have accountability, respectability and scientific viability and include evaluation and statistical information which would not be gained through more heuristic small-scale research (Etherington 2004). With the new research paradigms however, it is now being argued that there is a place for more democratic models of research that help us to understand ourselves, our clients, human experience and relationships in depth (Carson & Fairbairn, 2002; Etherington, 2004; Gilbert, 2002). Fully participatory, co-operative research with people as described by Lincoln (cited in Heron & Reason, 1997) allows us to join collaboratively with fellow humans in our inquiry. The acknowledgement that human beings exist in multiple strata of reality (Tedlock, 2000) supports the need for diverse and more creative research methods, which enable the individual experience to be used. This is a more involved and reflexive way of reaching a better understanding of the beliefs, motivations, meanings, behaviours and wider social context of the participants involved in the research.

Heuristic methodology is a process, which enables the researcher by inclusion to make a personal connection, relationship and exploration of a phenomenon, thus allowing analysis of the data through the researcher's tacit process. This leads to depictions of essential meanings and their significance to the researcher (Etherington, 2001). Heuristic research comes from an inner passion for the subject and involves a personal challenge of self-search, self-dialogue, self-understanding and self-discovery alongside the world in which one lives. It is an autobiographic process, which may also have a universal significance. This research process can enable intense and passionate commitment to the research by the researcher. The research question and methodology "flow out of inner awareness, meaning and inspiration" (Moustakas, 1990, p.171). The involvement of the researcher requires a search for qualities, conditions and relationships that underlay the

question, and an openness to visions, images, dreams, connections, reflections, intuition, awareness's and insights which emerge in that process.

My research process has been informed by Moustakas' 'heuristic inquiry' method (1990). This method requires total immersion by the "inquirer" or researchers to the point where a creative "incubation" enables and brings a new understanding or experience of the phenomenon. Moustakas describes six phases of heuristic research: initial engagement, immersion, incubation, illumination, explication and creative synthesis (see appendix ix).

Heuristic research encourages the personal experience of the researcher and the heuristic process of indwelling enables the researcher to seek a deeper and more extended comprehension of the meaning of a theme of human experience. "It involves a willingness to gaze with unwavering attention and concentration into some facet of human experience in order to understand its constituent qualities and its wholeness" (Moustakas, 1990, p 24).

Polanyi (1966, p.18) reflects on the process of indwelling as interiorisation: to identify ourselves with the teachings in question. He speaks of tacit knowing "as a way to know more than we can tell" and how this is achieved by not looking at things in detail but by dwelling in them so that we can understand the joint meaning of the object or phenomenon of study. The knowledge and meanings that underlies the explicit knowledge is fundamental. In applying this process to heuristic research, the researcher is required to look beyond the details and the particulars and become aware of the whole. By incorporating a variety of creative data I hope that there will be a broader, deeper and more dynamic reflection and understanding of the experience of bereaved mothers.

With heuristic research every question has a social and wider universal significance, and the focus is exclusively aimed at understanding human experience, filtered through human eyes, human perceptions and reflecting human feelings (Moustakas 1994; Richardson, 2000). The relationship between researcher and participant is more personal, collaborative and interactive and one that is centred on the question of how human experience is endowed with meaning (Ellis & Bochner 2000). The collaborative nature of the heuristic paradigm can enable a co-operative and shared production of the research by researcher and participants, with the participants contributing to the outcomes of the research, but also acknowledging the influence of the biography of the researcher (Riches and Dawson 1996). The validity of the research also rests on how the research is received by those who shared in the research and the wider community who are interested in the subject (West, 1998).

As a researcher integrating personal experience and reflecting openly upon my own process, experience and connectedness with this topic of research, I am part of the research, rather than a bystander or analytical observer. This is consistent with reflexive ethnographies, which range along a continuum where the researcher begins the research from their own experience, to being one of the participants, to the researcher's story being the focus of the investigation (Ellis & Bochner, 2000). This can be an intensely personal process in which the researcher becomes part of the resulting research narrative (Gilbert 2002). There are many researchers who have used their own experience within the research, particularly in the area of child death (Ellis, 1993; Talbot, 1997; 1998; Wheeler, 2001; Kagan, 1998).

There are several strands of this research, which are for me, as researcher, important: the research approach is perspectival rather than objective; I hope this allowed data to emerge and be discovered rather than proven. In heuristic methodology the researcher seeks to find “qualitative depictions that are at the heart and depths of a person’s experiences” (Moustakas, 1990, p.38). I wanted to be able to portray the essential qualities and meanings of the experience of the research participants by offering each participant the opportunity to describe their experience in their own chosen way of communicating.

The value of this research approach is that it affords the opportunity to hear the participants in their own words, albeit filtered through the choices made by the researcher (Gilbert, 2002), enabling participants to remain close to depictions of their experience and telling their story with increased understanding and insight (Moustakas, 1994). This may be in pictures, poetry, narrative or interview. Story telling is integral to research, as participants attempt to create meaning using narrative and metaphor to make sense of their lives and experiences (Gilbert, 2000; Riches, 2002), “When we use our own stories, or those of others, for research, we give testimony to what we have witnessed; and that testimony creates a voice” (Etherington, 2000, p17). “Narratives provide an ideal medium for researching and understanding individuals’ lives in social context” (Elliot, 2005, p.26). The demand upon the researcher is to be alongside the participant and to try and understand the world from their point of view (Riches, 2002). Wengraf (2001) describes discourse as a “linguistic performance” and it is my hope that the dialogue between participant and myself as interviewer is reflected as a joint ‘performance’ a shared journey.

I have chosen to refer to each participant's data as their 'story' because the narrative format I have used to present their data is sympathetic with narrative and story-telling. I have based my representation of the stories on the stanza format that Kim Etherington (2004, p 56) uses in presenting her research. "This breaks up what might seem a dense format that might otherwise be less accessible". This format will hopefully make the stories more readable, and allow for the pauses, the flow, and the natural rhythm and beauty of speech patterns, as well as retain a sense of the individual, enabling the reader to feel engaged and interested in the stories.

Sample

The five participants are bereaved mothers who are volunteer helpers at a bereavement service for those affected by the death of a child. Therefore the sample for this research is purposive, as opposed to a random sample, because the participants selected for inclusion are from a particular setting related to fulfilling the criteria (and also for ethical management). This enables an in-depth study of the phenomenon in question, whilst expanding the variability due to social, age and causal factors. The members of the sample all met the following criteria, but have also included some variation to enable more research areas to emerge and be analysed.

Criteria

- Research participants are bereaved mothers.
- They are current volunteers at a bereavement service in a hospital and have been assessed for their ability to support other bereaved parents. They therefore have a support network within the volunteer team and service, and counselling support if required.
- Their child who has died will have been between 1 and 21 years of age (approximately). This will exclude stillbirth, cot death and miscarriage, as these are distinct areas of research.
- A minimum period of three years has elapsed since the death of their child.
- In addition participants were invited to share any creativity they had explored in the time since their child's death.

The main variables of the sample include the uniqueness of each individual's experience of grief, the age of the participant, the age of the child, the time since their death and the individual experience of the child's life and cause of death.

Data Collection

The data of qualitative enquiry is usually people's words and actions and therefore requires methods that allow the researcher to capture language and behaviour (Maykut & Morehouse, 1994). Combining questionnaires and interviews in a multi method approach can offer a more integrative approach, however I chose to use face to face interviews to gather the main body of data as this approach seems more appropriate for the sensitive area of study which I researched. A skilful and empathic interviewer is able to respond to

the moment-by-moment experience with the participant and respond to the themes as they emerge in the interview. Whilst face to face interviews can enable sensitive qualitative data to be generated they are also more liable than questionnaires to be influenced by the personality or interpersonal style of the interviewer (McLeod 2003). This can be helpful to the interview process if the interviewer is alert and sensitive to the ebb and flow of the interview and the participant's needs.

There are different approaches to the structuring of qualitative research interviews from unstructured or open-ended interviews, to structured interviews. I chose to use a semi-structured interview approach because of the vastness of the subject and to enable a structure for the participants to follow in what is a very sensitive and emotional experience. In addition I had particular areas of focus that had emerged from the literature review which I wanted to explore. This kind of interview can be highly effective when the researcher feels able to anticipate in advance areas which she intends to investigate (McLeod, 2003). Wengraf (2001, p.3) describes the research interview as a "conversational interaction" where the questions are only "partially prepared in advance" and "improvised" by the interviewer. He describes the interview as a "joint production, a co-production" between interviewer and participant. Questions therefore needed to be clear and unambiguous and linked to the focus of enquiry, open and not closed enabling descriptive and creative data, as opposed to inhibiting and limiting the data. I did conduct a pilot interview with a bereaved mother and she stated that the subject was so vast that she found the structure of the questions helpful as they gave her a focus.

The interview process was described in written form to the participants before commencement. This included an information sheet (appendix i), accompanying letter

(appendix ii) and the interview themes (appendix iii). The information given included explanation of the rationale for the research, the process of the interview (one to one and taped), how information would be used and issues of confidentiality. Participants were also offered the opportunity to have a preliminary meeting to ask questions and for further clarification if required. It was explained that at this stage there was no commitment and may not necessarily result in an interview. Before I commenced the taped interview, I asked each participant if they would prefer to choose a non-identifiable name to be referred to in the research instead of “participant 1, 2” etc., allowing participants a choice about how they would like themselves to be referenced. All five participants chose a name, and for all of them there was a reason for their choice, either symbolic or simply because it was a name that they liked.

Each interview lasted between one hour and one hour and twenty minutes. During the interview it is the qualitative interviewer’s job to be alert and responsive and to sense the opportune time to ask a question (Maykut & Morehouse, 1994). Whilst the interview needed to have a basic structure, to enable information to be useful for the research and researcher, the participant was the most important part of this process. It was paramount that they were allowed the time and space to tell their story and feel they were able to leave the interview feeling supported and knowing where they could go for support if needed.

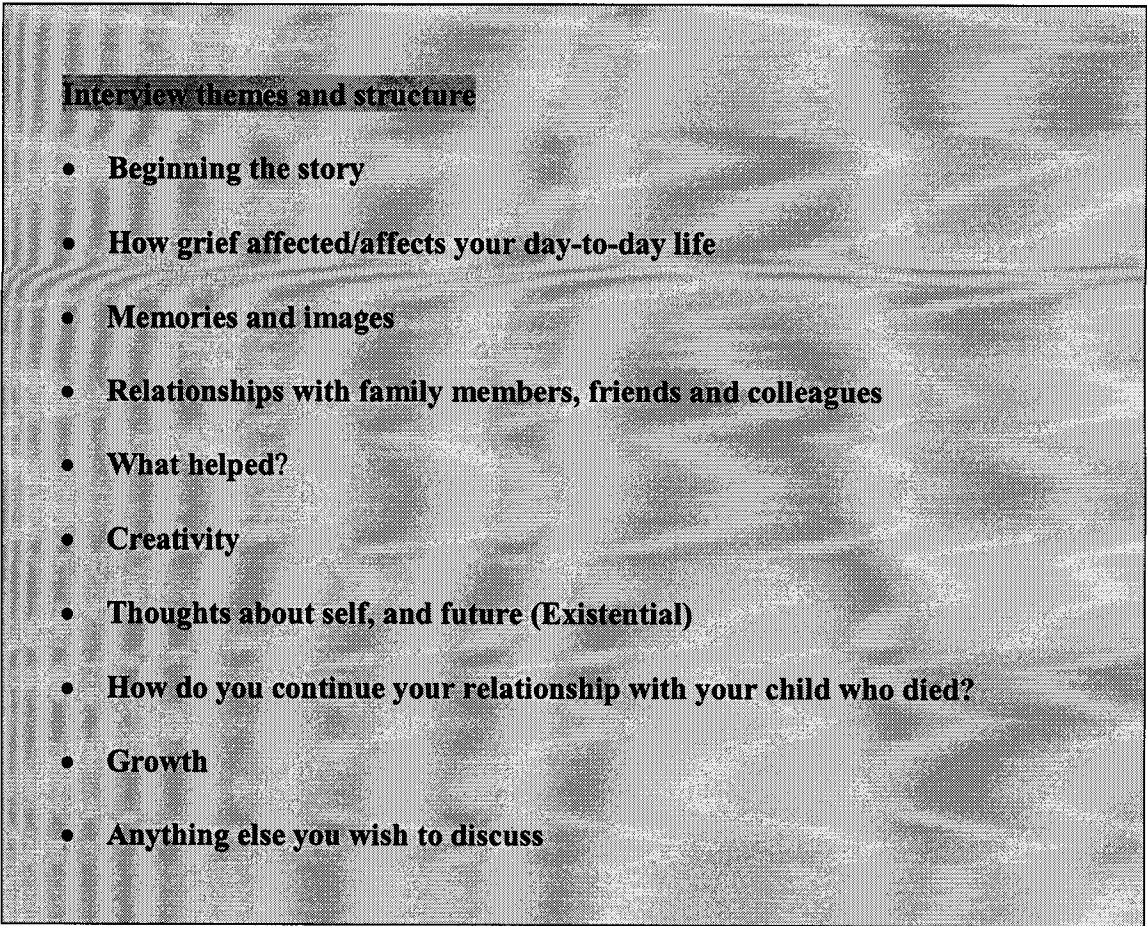
Whilst I had interview questions, if a participant was covering those areas within the interview, or had moved into another area, I was not rigid. Therefore some participants were not asked every question, depending on the flow of their story and how they were within that process. Whilst the interview had broad themes and questions, further varied

data emerged within those themes from each participant. I was mindful of responding to the individual and their needs, and the bereaved mothers who participated in this study reflected upon how enabling the interview process was for them and how helpful it felt that I was also a bereaved parent and had a level of personal understanding.

Creative data such as poetry, narrative, diary entries and photographs of creativity activities and interests were also collected from the participants during the interview. Three of the participants offered writing, which they had done during the early stages of their grief to express and communicate their experience, and two offered photographs showing the creative activities they had engaged in. One participant did not use creativity.

After the interviews were completed and transcribed it was vital to provide the opportunity for participants to review the transcript and any other data. This enables the participant to have appropriate control over their data or story, to verify the accuracy of the account and assess the overall adequacy, as well as confirm particular aspects of her story (Gilbert, 2002). I offered participants the full transcript to read and feed back any changes they wanted. Some of the participants made minor amendments.

These are the broad themes, which formed the structure of the interview with participants. A more detailed structure with specific prompts is in appendix iii.



Data Analysis

Analysing data can be seen as varying along a continuum ranging from low level to high level of interpretation and abstraction. Maycut and Morehouse (1994) present the work of Strauss and Corbin (1990): One approach they used requires some selection and interpretation of data, and a weaving of descriptions, words, field note quotations, and the researcher's own interpretations in a rich and believable way. Moustakas (1990, p.174) maintains "the focus in a heuristic research quest is on the re-creation of the lived experience, full and complete depictions from the frame of reference of the experiencing person". I used these approaches to inform my inductive data analysis, which allowed research findings to emerge from the "frequent, dominant or significant themes inherent in the raw data" (Thomas, 2003, p 2).

More specifically Moustakas (1990, p.54) described a process of data analysis, which has formed the basis of my own.

Heuristic Data Analysis

The heuristic researcher returns again and again to the data to check the depictions of the experience to determine whether the qualities of constituents that have been derived from the data embrace the necessary and sufficient meanings.

- Constant appraisal of significance
- Checking and judging
- Verification and explication of the phenomenon
- Creative synthesis of essences and meanings
- Reflection on and analysis of verbatim transcribed interviews and other material
- Portrayal of phenomenon investigated
- Checking for accuracy and comprehensiveness by sharing data with participants

Analysing the data began by gathering the varied data from each participant and then organising, handling and synthesising data (Moustakas, 1990). During this period I immersed myself in the data, revisiting it, listening to the taped interviews, transcribing each interview, reading, then transcribing again into a stanza format. During this time I would set each interview aside and allow myself to be for a while, as tacit and unconscious processes would occur. I would then revisit the data and get a sense of both my intellectual and internal process as I read and re-read the narratives whilst also

experiencing the physical and tactile process of holding the narratives. This stage was moving and powerful, and at times required space for reflection. I found myself connecting strongly with each participant and almost absorbing a sense of them and their child. This was profound for me, and the stage where I needed to look after myself.

The next stage involved extracting the qualities and themes which had emerged within the structure of the interview, whilst retaining the qualities and essence of the participant's experience, story, words and style of communication. Often themes would become illuminated and would come to my notice and sometimes I would be surprised by something that I had not seen before. I revisited the original transcript, checking if it fit with the themed data, which had now been extracted, to see if it still retained the true essence of the participant's experience. Once I felt this was complete, I then moved onto the following participant's interviews.

After this stage a further period of reflection and immersion was needed to allow the universal qualities of all of the interviews to be experienced, internalised and understood. The next stage was to combine and create a composite depiction of the "whole", which included all five participant's stories and the core themes and meanings of the experience of these bereaved mothers. This was to enable synthesis of the meanings and then comparison and connection of all common themes and also any divergent themes within each transcript. Identifying text segments, which contained units of meaning, by using coloured pencils to code each shared and unique theme on the transcripts, helped to further draw out meanings and themes. The constant comparative method was used as a basis to inform this process, and inductive codes were assigned to segments of data that described the themes, which emerged. I was also mindful of allowing some freedom to be

less prescriptive and structured, as I felt this would interfere with the heuristic process, which I wanted to trust. Themes emerged from the units of meaning, and I included verbatim extracts, narratives, and descriptions from each participant as a way of maintaining the individual portrait of each participant and their story within the outcomes. I also integrated any creative data previously collected.

Capturing and expressing an understanding of the subject of research may involve moving into a more creative and responsive way of researching and presenting the rich data (McLoed, 2001). The qualitative researcher “may be seen as a bricoleur, as a maker of quilts” (Denzin & Lincoln, 2000, p.4) and uses the aesthetic and material tools of his or her practice, deploying methods most appropriate to the subject being researched. The researcher in responding to the nature of the research pieces together and even creates their own means of portraying the subject, which fits and reflects the very nature or complexities. “This process of *montage* creates and brings psychological and emotional unity to an interpretive experience” (Denzin & Lincoln, 2000, p.5). Flick (1998) suggests that such triangulation adds rigor, breadth, complexity, richness and depth to any inquiry.

By organising and synthesising the breadth of heuristic research data collected, individual portraits were created in a sequence that tells the story of each participant. The primary researcher develops a creative synthesis (Clark Moustakas, 1994), to filter the information they receive and co-construct the finished narrative; the role of the participant is to tell their story and to be assured that the person listening will treat them and their story with respect (Gilbert, 2002).

In weaving together different methods of ‘telling’ I hope I have been able to interpret and tell the story of the participants, in a way, which reflects the richness of the ‘quilt’.

I am aware that for a small-scale study, this has been difficult and therefore I have limited my data to interview, narrative and poetry in the main text, and have used an appendix for the thematic narrative transcripts, which tell each individual mother’s story. This felt very important to me, as I could not leave out these powerful and beautiful stories, which the women had bravely shared with me.

I hope that this research will provide themes and insights reflecting the experiences of those who participated in the study, and may enable a depth of understanding into this intensely painful human experience.

Ethical Issues

Because of the sensitive nature of the research topic and the potential vulnerability of the research participants it was vital to ensure that support was available if needed. Whilst I certainly do not wish to undermine or diminish the coping strategies, self-awareness and insight of bereaved parents, it is important and ethical that support was available.

Prior to the interview participants had received information and a letter inviting them to participate and informed consent was requested, a contract signed and copy offered (appendix iv).

The ethical principles of beneficence, nonmaleficence, autonomy and fidelity (BACP Ethical Framework) were respected throughout this research. My aim was to act in accordance with these principles, however I would also like to add that whilst

nonmaleficence (avoiding harm) is paramount, there might also be benefits for participants in telling their story and being heard. I believe that research participants were able to engage in their own story, and through the opportunity to participate, contribute and read others' contributions, may have experienced benefits. In fact some of the mothers have since fed back positive experience of the process and having their own transcript to share with others. Angela telephoned me, having received a copy of the transcript of her interview and thanked me for helping her tell her story. She also said that she and her husband had read it together and were sharing it with their children and grandchildren. She described the transcript as "a gift" and thanked me for it; I felt very moved by this. Helen told me that she had taken her transcript into the Bereavement Centre to share with a colleague where she received positive affirmation of her story.

The interview structure was designed with ethical management in mind. The questions began with the death of the child and ended in the here and now of the participant's life. My focus at the end of the interview was on hope and growth, as a way of enabling participants to move back into their current life in the process of the interview.

This ethical consideration also extends to the reader of my dissertation, who may also experience vicarious traumatising when reading, and to myself as I wrote up each transcript with its painful and traumatic content. At times I was very aware that I was experiencing a level of vicarious trauma whilst transcribing and immersing myself in the data, and the structure helped me to end each transcript with hope and sometimes joy alongside each individual's story. So, the choreography of the questions is enabling a safe ethical management of the story for participant, reader and researcher.

The Bereavement Centre had counsellors available to offer support to the participants should they need it. Riches and Dawson (1996), when researching bereaved parents were able to focus on this area of research by having links with a number of self-help bereavement organisations. I believe that working collaboratively with the Bereavement Centre has enabled the research to be ethically managed. It has also meant that I have had a singular role with the research participants, as that of researcher. McLeod (1999) raises the issue of ethical dilemmas when working in a dual role as counsellor and researcher. He also sees difficulty when collecting data from colleagues within the same agency. My involvement with the Centre was separate in this sense.

Because my research involved participants who were volunteers within a Bereavement Centre within an NHS hospital, my research had to go through the rigorous process of COREC: NHS Central Office for Research Ethics Committees. This involved submitting a thorough research proposal and attending an Ethics committee to evaluate and approve my research. The research proposal also needed to be approved by the Department of Social and Communication Studies Ethics Committee.

My enthusiasm and commitment to the research has also needed to be assessed objectively. It is necessary for the researcher to imagine herself in the role of the participant and think of how it would feel to be part of such a study (McLeod, 2003). In acknowledging my own experience as a bereaved parent I was aware of the potential of issues being raised for me and of the need for self-care and support whilst carrying out this research. This is where supervision was vital as well as personal and professional support networks.

I believe there were benefits to the research participants knowing that I am a bereaved parent, in fact all of the participants stated that they felt more comfortable knowing this. They may have felt that they were participating and not being observed by an outsider or an expert. I also think that my responses during the interviews demonstrated not only my deep empathy for them during the interview process, but also an inner knowing and connection with what it is like to be a bereaved mother. I believe that this enabled a safe management of some of the ethical issues that were pertinent to this study and the potentially raw and painful nature of the interview process.

Maintaining confidentiality is vital to enable the respect and prevention of harm to research participants. It is not only beneficial to the interviewee, but also good practice on the part of the researcher. Explaining confidentiality offers confidence to the research participants in the researcher's ethical practice. The processes ensuring confidentiality were explained in detail to participants, including anonymising data by using a pseudonym, removing all third party information and data relating to places and names which could connect with the participant.

Identifiable data needed to be kept separate from any other research data. Data was coded, and the key to the code kept secure. Reference was made to the BACP Ethical Framework for Good Practice in Counselling and Psychotherapy, Ethical Guidelines for Researching Counselling and Psychotherapy, and also the Data Protection Act.

Trustworthiness

The findings of any qualitative research are generated through the “active personal engagement of the investigator with the phenomena of interest” and therefore will “bear the mark of the investigator’s approach” (McLeod 2001, p 182). Trustworthiness refers to the believability of the researcher’s findings (Lincoln & Guba, 1985) and evidence of how the researcher has designed, carried out and reported the findings. Can we place confidence in the outcomes of the study and believe what the researcher has reported (Maycut & Moorhouse, 1994)? “In quantitative research the notion of validity refers to the capacity of a measure to capture accurately or reflect some characteristic of objective reality” (McLeod, 2001 p182).

Making the research process transparent by offering detailed description of the research process and outcomes provides the reader with a basis for judging the credibility of the study (Maycut and Moorhouse, 1994). By describing my research process and outcomes in detail, I hope that I have offered some credibility and trustworthiness to the research. McLeod (2001) holds the view that research can only be meaningful for readers and participants if it is approached with “sufficient openness and integrity on the part of the researcher”. I have tried throughout this research to uphold Rogers’ core conditions of empathy, congruence and acceptance.

Maykut and Morehouse (1994) highlight four main principles which contribute to trustworthiness. These principles help to make the research process visible, and I applied them to my research to ensure credibility.

- Multiple methods of data collection: *interviews, observations, diary entries, poetry, photographs, narratives*
- Building an audit trail: *Researcher's journal, interview transcripts and field notes, narrative transcripts included in additional volume, unitised data, constant comparative data analysis process. Enabling people to "walk through your work from beginning to end".*
- Working in a team: *Communicating with other theorists and researchers throughout, working together with the manager of the Bereavement Centre and supervision.*
- Member Checks: *checking with research participants that I have accurately described their experience. This involved contacting participants and offering transcripts at various stages to enable changes and also offering the opportunity to withdraw at any point in the research.*

An important aspect of this research, which enables the reader to judge the validity and trustworthiness of the data, is the voice of the participant through their own narrative, which has been included within the outcomes and the discussion. Whilst tape-recorded interviews and verbatim transcripts form the foundation of the data collection, there is also rich data which supplements and adds further meaning and depth to the descriptions of the experience of the participants. Moustakas (1990, p181-182) asserts that the material collected must depict the experiences in 'accurate, comprehensive, rich and vivid terms.' The 'depictions' I have presented are in photographs, stories, journal

entries, narratives, poetry and metaphors. From the original transcript for each participant I extracted meaningful data into narratives in a stanza format, and those individual narratives are included in the appendix, providing the reader with the opportunity to explore each story and also providing a data trail. For the outcomes I used verbatim extracts thematically, which were taken from the individual narratives.

It could be argued that researchers have a responsibility to remain close to the stories and experience of their participants (Gilbert, 2002). Therefore, if the explanation of this experience is to be trustworthy (Maykut & Morehouse, 1994) I needed to stay close to the depictions of the participants and also enable their unique voice, individuality, and language to provide the reader with a true sense of the person and their experience. I hope that this research has enabled the participant to be 'seen' and 'heard'.

Gaining feedback from participants through member checking is valuable (Maykut & Moorhouse, 1994) and further enables truth to be established. Setting the outcomes within the context of research and available literature further supports and offers confidence to those who read it. I have been rigorous in grounding the findings of the research in current and past research.

Limitations

There are clearly limitations with such a small-scale study. Whilst the data emerging from this research is reflective of much of the current research available, I am also aware that there are other variables, which are by the very nature of a small sample perhaps not present, therefore hindering generalizations. The mothers interviewed were all bereaved parent volunteers within a Bereavement Centre. They were supporting others and were

engaged in a positive and nurturing role within the nature of their volunteer work; consequently they had a network of support from other bereaved parents with whom they worked. This can enable a focus for grief, a bond with others and a subsequent focus to their lives, which other bereaved mothers may not have. All of the bereaved mothers were white, from the UK and had been married at the time of their child's death.

The sensitive nature of the research meant that only mothers who had been bereaved for a minimum period of 3 years could be involved and the volunteers who came forward had been bereaved for a minimum of nine years. This may have meant they were in a different place in their experience of grief, in contrast to mothers more recently bereaved, for whom there may have been different outcomes. All of the mothers interviewed continued a relationship with their child who had died, however I realise that it is possible that some bereaved mothers may need to sever the bond and relationship to survive.

The limitation of words for such a small-scale piece of research needs to be considered when looking in depth at some of the themes that have emerged within the data. For that reason I have included the stanza narratives for all participants in the appendices. I would recommend that readers take the time to look at these, as they more accurately reflect the journey and experience of the mothers who I interviewed.

Outcomes

Themes within interviews with bereaved mothers – *Quotes and references from the participants are coded with their initial and also the page number from their narrative transcript, which will be found in the appendix.*

Each participant chose a non-identifiable name, which they would like to be referred to.
A – Angela ≈ E – Elizabeth ≈ H – Helen ≈ J – Janet ≈ K – Kate

Each participant’s child who died is referred to as “C”, their partner as “P” and any other children are referred to as “S” (son) or “D” (daughter). No identifiable data related to place names or persons is included.

I interviewed five bereaved mothers who were bereaved parent volunteers at a Bereavement Centre and were aged between 42 and 63. Their children were aged between 9 months and 25 years of age when they died. The causes of death were Cystic Fibrosis, heart condition, disabilities, cancer, and one who died in a nationally reported tragedy. The period of time elapsed since the death of each child was between 9 years and 22 years. Four of the mothers were married and one had been divorced since the death of her child.

Angela

Angela’s youngest child and son died in 1986. She has older children and grandchildren, and she described a long and painful journey, which lasted over many years to come to the place where she is now in her life. She said “I feel like I have been through life and death here on earth” but also reflected upon the joy that she had experienced during more recent years and “the new me that has emerged out of this, like a caterpillar out of its cocoon, like a butterfly”. Angela wondered prior to the interview if she had anything to offer to the research and whether her story would be of value. Her ability to describe her experience in exquisite language and metaphor has been profoundly moving.

Elizabeth

Elizabeth's daughter, and only child died in 1984. The "impact was absolutely immense because every single thing revolved around C. The void was immense." Elizabeth made some huge life changes, which included the end of her marriage. She is determined to show herself and others that "you can really get through these things" and lives her life "bittersweet", with new pleasures and "enriched by a load of new people and two new children", but also with the loss of her daughter in that life. Elizabeth described herself as a very private person, and I am grateful that she was able to share with me her private life and loss and some very poignant reflections about her journey.

Helen

Helen's only son died in 1992, and she has daughters and grandchildren. She described the sudden news of her son's illness and how she went abroad alone to be with him. Helen described the "deep dark hole" that she put herself in after his death and how she felt others did not understand. In her life today she described much pleasure and fun, especially with her family and an awareness of the world, people and nature. An aspect of Helen, which became clear in her interview and subsequent contact, is her wonderful sense of humour and passion for supporting others, including this research.

Janet

Janet's first son died in 1992. She has subsequently had another son. She talked about the huge memory loss she experienced: "I think I just shut down" and describes how there are gaps in her memory of her life during the period after his death. She spoke of the need to have another baby and how the bond with her husband was strengthened by the need to have another child. Janet developed a passion for gardening, flowers and creativity to express her connection with her son; "it's like a connection with him, it flourishes because it's part of him, it's because of him." Janet works full time and has a strong and committed connection with the Bereavement Centre. We shared a sense of connection related to the fact we both had two sons and one had died.

Kate

"I have three children and C was my eldest." Kate's son died in 1989, and she described the "exceptional family life" that she had before his death. She spoke of the period of searching for answers and justice, "I wanted to know everything". She reflected on the "slow decline" into her grief, which left her debilitated and in a place where she wanted to die. Kate's life today is one of a reengagement in family life particularly through her grandchildren. She described herself as "placid" and "more assertive about what I believe in". Kate has participated in interviews and research before and realised when she was interviewed for this research, that she is now ready to move forward from telling her story. I am grateful to Kate for her commitment and support for this research.

I have broken the individual narrative transcripts up into themes emerging within the main themes, as a way of reflecting the emergent outcomes of the interviews.

Grief

Nobody can ever take away your loss,
nobody can ever take away your grief,
and it will be with you 'til the day you die. (*K p11*)

Grief affects people in many ways and the bereaved mothers interviewed spoke of the emptiness, loneliness and isolation they felt and the intensity and depth of suffering they experienced. Some talked about the experience of pain in both an emotional and physical way, and how that in turn affected their day to day lives and ability to function.

..and I didn't realise
that clinical depression had set in. (*A p3*)

I was so strong and stayed together.
I don't know how?
.. I needed another baby to hold...
because I had nothing then. (*J p4*)

I, from that point on went into a slow decline.
...and when I was at home, I wanted to go out,
and when I was out I wanted to be at home. (*K p3*)

I wanted to know everything,
I had to find out,
But that consumed my time really. (*K p4*)

Emptiness

.. an emptiness inside. (*A. p2*)
It was like being in an empty room.
This was all part and parcel of grief,
...whatever grieving process means? (*A p3*)

The void was immense
and I actually felt very redundant. (*E p1*)

No matter what people tell you,
you have always got that big hole. (*J p10*)

Suicidal thoughts

...and I actually thought about taking my own life. (*K p3*)

Oh, I didn't want to be here.

It was too hard.

Because at the beginning I wanted to kill myself. (*J p7-8*)

Physiological

I can remember... the physical pain and the mental pain,

.. I am convinced it went into my body.

I couldn't even explain how I felt.

I just felt I was in a vice.

Sleep

I can still wake up in the night feeling very, very tense.

I know I will never be the same.

I could have slept my life away. (*A p3*)

I didn't sleep much, for a long, long time.

I just wasn't tired. (*E p2*)

Withdrawing

In the midst of the support of family, friends and colleagues the mothers reflected upon the contradiction of the feelings of isolation they experienced and how each had a strong need to manage their grief on their own first, before they could let others back into their lives. During the period of withdrawal what emerged for most was the need to either find a lost self or develop a new self and the need to be in that deep and very dark place for a while before they could move forward with their lives. Two spoke of the need to consider their own death as an option or possibility before choosing to live.

I didn't like standing alone,
but maybe I needed that time. (*A p4*)

I suppose I was putting up a barrier really,
I didn't want anybody to come anywhere near me
..that could hurt me. (*A p6*)

I built walls,
..I just turned into myself.
I couldn't share how I felt,
because I didn't want them to see me as weak as I was.
I just wanted to be Elizabeth again, I just wanted to be me. (*E p3*)

I put myself in a hole.
And I didn't like the hole,
but I felt OK in there,
and I got to like it. (*H p5*)

I didn't have any connections with anyone. (*H p6*)

I don't know quite what triggered the memory loss.
....I think I just shut down. (*J p4*)
I didn't want to know anybody. (*J p6*)

Anger

Three of the participants spoke of experiencing anger and the importance of expressing it. They reflected on how anger can be destructive and hard to make sense of, and the difficulty in finding a way to communicate it, but also how necessary anger is to preserve survival.

He says he doesn't know where I got the strength.
I just wrecked the whole place. (*A p16 **)

It's like the old saying
"you only hurt the one you love" (*A p6*)

It was like I had so much anger that I couldn't express it. (*J p4*)

They say that anger is not good,
but in some forms anger is better than the place where I was in wanting to die
and wanting to be with him. (*K p4*)

** Taken from original transcript*

Relationships

Grief separated and isolated the participants from others and they experienced a loss of joy and feelings of pointlessness to their lives. This resulted in withdrawal from relationships with immediate family, friends, colleagues and neighbours. Four of the mothers spoke of the initial pressures on their relationships with their partners and then how they became close again. The impact on sexual relationships was talked about and how for some it was difficult to have intimacy alongside the feelings of loss, whilst for one mother the intimacy was necessary to cope. One described the need for another child and how that brought an intimacy and bond between her and her husband. For another the relationship with her partner ended as a result of her child's death.

Partner

He couldn't feel my feelings,
He had his own feelings,
Men do grieve differently, don't they? (*A p6*)

It was difficult to talk even to my husband.
Trying to protect each other all the time. (*A p5*)

Coping

By then we were well apart.
Even in just our ways of thinking,
and what we wanted out of life. (*E p4*)

I just knew I didn't want P there.
I didn't want P to feel how I felt.
I couldn't cope with him having to deal with it. (*H p7*)

P went back to work, he had to.
Three years later he collapsed.
..men do this "I'm ok routine" and "I'm holding everything together." (*J p7*)

He kept saying to me "don't shut me out."....
He seemed to me to be coping very well..
..he wasn't coping very well at all. (*K p5*)

Intimacy

I found my husband intolerable, I couldn't bear him touching me.

....I wanted him to understand how I felt,

but he couldn't possibly understand.

I couldn't even tolerate his kindness. (*A p5*)

It was almost like we had to have that closeness.

...we had a purpose,

but also we just needed that comfort of each other,

We were very together at the time. (*J p7*)

And I also missed the closeness I had with my husband...

because how could you do something that gave you so much enjoyment

when there is so much sadness in your life. (*K p5*)

Family and Others

I didn't want the phone to ring,

I didn't want to see anyone,

I couldn't face anybody. (*A p4*)

Always protecting people,

not for myself,

always for others. (*A p7*)

But, I could not be responsible for anybody but myself.

I wanted to be a mum, but I couldn't be...

I wanted to go back to just being me.

I couldn't cope with the fact they wanted to love and care for me. (*E p3*)

I didn't need anyone,

I didn't want anyone.

I couldn't be bothered with people. (*H p7*)

I didn't want my friends around,

I didn't want my family,

I didn't want anybody. (*J p6*)

My friends had been forgotten,

I never picked up on my friends.

There were a few of them that soldiered on. (*K p5*)

Children

Some of the mothers remembered how their children were trying to reach out to them and offer support, but they were unable at first to reciprocate.

And (son) put my arm round him and said "will I do mum?"
And we lay like that, and the pair of us just cried. (*A p6*)

I didn't want to look at my daughters,
I couldn't handle their hurt
...I pushed everything behind me. (*H p7*)

she (daughter) said,
"the hardest part was looking at you and people were in the house
And you weren't aware they were there." (*H p8*)

And these two children were determined that they would protect me.
And I wasn't even aware that they were around. (*K p5*)

Reconnecting

It really has been a horrendous journey.
So, now I am well connected with my friends, my family. (*A p9*)

It was well over a year, eighteen months,
I was beginning to go into the family circle again. (*K p8*)

Memories and images

Three of the participants talked about dreams, images and senses that connected them to their child. They spoke of the sense of presence, connection, comfort and acceptance, which dreams offered and also feeling connected with their child.

Dream

.. I said to the woman "do you mind if I just take him?"....
and I just felt this overwhelming love and happiness....
It was a very profound dream. (*A p5*)

Images

And I could always remember her, I could see her doing different things...
Rainbows are our biggest connection...On my birthday, the biggest rainbow came.
I honestly felt, she is actually thinking of me. (*E p3*)

Senses

Sometimes when I get the feeling of him,
I get the smell of my grandmother first.
And I know she 's with him.
It's almost like , oh, here, they've come together. They're together. (*J p6*)

I think that she actually makes sure that I am doing the right thing. (*E p8*)

..and I just knew he was there.
And smell, you know you get the smell of them,
The touch on your face, his cheek...
It has been a comfort, a great comfort to me. (*J p5-6*)

What helped

Re-engaging in life after the death of a child can take many years. The mothers reflected on what helped and what didn't and the changes they had needed to make in their lives and to self to adjust. Whilst for some there was a strong need to make sense of what had happened to their child through the pursuit of answers and finding meaning, there was also engagement in new interests and activities which helped them to become involved in life again and resulted in significant lifestyle changes and re-ordering of what was now important and supportive to their sense of self. Angela, Helen and Kate spoke of the benefits of walking and how that enabled space for self to reflect. The participants are volunteers at a child death Bereavement Centre and they all found benefits, support, comfort and strength from their experience of sharing, helping and being with other bereaved parents.

Bereavement Centre and other bereaved parents

To be together, to share, so for me the Bereavement Centre,
..it was a gift. (*A p7*)

So, I suppose part of my life is the Bereavement Centre. (*E p5*)

I love the Bereavement Centre. (*H p8*)

I just knew that I needed to be with somebody else who felt like me.
Our biggest help was talking to the other parents.
Getting involved. (*J p8*)

Reconnecting – re-engaging

Re-engaging in life,
...picking up the pieces of the life I had,
And building on my self-worth.
Getting back in touch with others and getting in touch with myself. (*A p7*)

I am more open to listening to people
and to letting people in re me. (*E p5*)

Yes, I had to change my lifestyle,
....I had to come away from people
who I thought had no conception of life at all. (*K p6-7*)

Interests

At the time it was the garden.
...I bought Azaleas, because C like Azaleas.

I played golf and I played tennis.
..and the other part of my life is the children,
and I have a social life, so that's the good part about it. (*E p5*)

Finding Purpose

We did television interviews ..
And while I was doing that I was quite strong
because I thought there was a purpose to it.
Purpose to that while as I said detrimental to everyone else around me.
And I had to do it for C.

I decided that I wanted to pack in my job...
and that I needed to find something
which would give me an inner peace. (*K p6-7*)

Nature and Landscape

Three of the mothers reflected upon the benefits of walking and how this enabled a space for self to feel a sense of freedom to reflect and be.

I was free and uninhibited about anything..
I just felt at peace.
I was free from the vice. I was me....
I connect with my joy when I am walking. (*A p10*)

I love walking in the wind...
and kicking all the leaves in the autumn. ..
I am aware now of the world. (*H p9*)

.... and I did a lot of walking...
when I went out my shoulders were up to my ears,
and when I came home I was in a more relaxed state. (*K p6-7*)

Creativity

Angela, Elizabeth and Helen used the creative process of writing and poetry to express and communicate their feelings and thoughts to self and others. I have included extracts within this data, and the complete poetry and writing is in the appendices.

For Elizabeth her first piece of writing was written sitting in her daughter's room in the year of her death (Appendix v). It was her way of trying to explain and communicate to friends and family how she felt.

In sleep I am closer to C
But sleep doesn't come easy
How can I say how much I hurt
Hurt is in my heart....
The tears just flow
I think of something
See something
Hear a song
I still have to respect other people's feelings
but its not always convenient for me to talk
and then the moment has passed

Elizabeth's second piece of writing is Appendix vi.

Angela wrote her poem (see appendix vii) after a therapeutic weekend with other bereaved parents.

So we danced and we sang, let our spirits go free,
Let go, don't hang on, that's not for me.
If only and why, has no answer for me
So I dance and I sing and I giggle with glee.
I've a child in my heart who wants to play and go free
Why stop him? Just let him be, as he lives on in me.

Helen wrote a letter six months after her son died (appendix viii) as a way of describing the "deep dark hole" she was in.

I am in a deep dark hole,
I didn't fall in,
I put myself in.
I don't like it in here,
But I don't want to come out.
Nobody can touch me or approach me

Janet started to have an interest in flowers and express herself through flower arranging and also gardening.

I started to have this interest in flowers.
But, something that my mum said I always did when I was little,
but I never knew I had done it, you know.
And I started to do flowers on the cemetery, and rearranging things.



And then gradually we just started bringing everything home that had grown.
And we found that when we put it in the garden, it just flourished.
And so we started planting things purposely to bring home. (*J p 12*)

The bereaved mothers described significant changes in their lives and their view of the world resulting in a subsequent re-ordering of their priorities and life focus. Some spoke of the impact their experience has had on how they understand and relate to others on a deeper level and of a deeper appreciation, valuing and love of people and of life. One mother reflected that she felt less tolerant of people who complain or are critical and negative of others. Participants spoke of experiencing peace, richness, fulfilment, of an enjoyment of life and a sense of joy and pleasure, alongside the grief and loss of their child and the knowledge that this change had come out of something very painful. They also explored meanings about life, death and spirituality and for some a changed view of the world. The themes emerging within this theme are profound.

I feel I have got to know myself now. (*A p9*)

I am aware now of the world now. (*H p9*)

And I thought, I have got to find me. (*K p7*)

I wouldn't be who I am, where I am now. (*J p9*)

I believe it has given me a level of understanding and sensitivity
that I didn't have prior. (*J p12*)

The following further themes emerged within this category:

Spirituality

I wanted to give what I could to my grandchildren
in the way of spiritual, psychological,
to pass on something to them
that will help them to grow in their lives. (*A p11*)

And I honestly believe that probably that was what was meant to happen in the end,
....I just now think that somebody, whether it was C or whatever,
somebody led us to this. (*E p9*)

I started to go with a friend to spiritualists and faith healers ...
thinking to myself "well, if I find out where C is, I'll find out where I am."
But, it didn't work...
I went looking for spiritual healing. (*K p8*)

Beliefs and meanings about death

I think it is all connected to him.
I think it all links in.

..it's caused me not only to reflect on the life and death of C,
but the life and death of my own life really.
Because I feel like I have been through life and death here on earth. (*A p11*)

I have no fear now of death.
I do believe I will meet C again and I do trust that,
but if I don't it is not going to make any difference. (*E p7*)

...this has happened to us, for a reason.
In a lot of ways people say
"I wish it never happened and I wish I could have my son back."
..half of me thinks, if I didn't have this experience,
I wouldn't be who I am, where I am now. (*J p9*)

....and here was all this healthy green mistletoe
growing on this dead tree...
and I thought "well, this is the new life,
this is new beginnings", you know?
"This is life coming out of death."

I am now the mistletoe.
The new life. (*A p10*)

Continuing the relationship with child, the bond.

Each mother spoke of the importance of keeping their child's memory alive and of an ongoing relationship with them in the here and now. Some continued to have conversations with their child who had died, include them in conversations with family and friends and imagine what they would be doing now. Others described rituals such as

buying gifts, lighting candles at particular times of year, playing music that was connected, or having interests which continued the connection. Linking objects associated with the child was a theme, such as the importance for some of the child's room or possessions. What was evident with all participants was the importance not only of keeping the love alive but also the conversations about their child, past, present and future.

Continuing the connection and relationship

You live and breathe for your child..
It is about a relationship between a mother and her child. (A p2)
I also believe that life goes on...
He continues on,
the love.
C's just inside of me....
And I have this freedom to know that he lived,
To know that he died,
And to know that he is still part of our family. (A p11)

Linking objects

It's a part of our way of life, it is used.
Hundreds of people have slept in there but it is still C's room.

I still play the record,..
But, I enjoy playing it now its ok to cry, its ok. (H p9)

I have been quite creative that way with flowers and trees and things because,
I feel as if it's living, it's life...
It's like a connection with him,
it flourishes because it's part of him.

And in that tree, you know, you've got two sunflowers.
We never planted sunflower seeds.
When he died,
the first thing that somebody gave me was a sunflower. (J p9)



(picture of the sunflower in Janet's garden)

Conversations

We don't stop talking about her, even though there are two other children
in my life now. They know all about her,
I have always said that C is here with me anyway,
She's never left me.

And I am wanting her to be proud of me.
Anything I do, I do for her. *(E p7-8)*

Yes, one of the biggest things of losing a child that I find, is that after a period of time
they are never mentioned, never.
So, if I feel that that's happening,
I will instigate a conversation. *(H p9-10)*

Keeping his memory alive was very important to me.
Keeping talking about him a lot.
But what was important for me was that when B (brother) was born,
he knew who he was.
Never ever left me.
I always like to think he is with his brother as well. *(J p9-12)*

Everything connects,
... and I could hear him saying in my head, "I always knew she'd be there."
..but he is there with me on my holiday.
And I ask him "well you have been here before so what do you think of this?" *(K p8)*

Rituals

There are things that will always probably be there
and things that I will always do.
Yes, as a connection. *(E p7)*

Christmas cards,
if we go on holiday,
postcard will have the four names on.

Those three candles were the representative of the people,
and we lit those just before she came up the aisle.
He's here, oh yes. He's never gone away. (*J p9-11*)

I always find a cathedral,
I always light a candle and talk to him in the church when I go. (*K p8*)

Gifts

Yes, and I bring him a present back,
sometimes wind chimes for the cemetery..
Because the others get a gift, he gets a gift.

Christmas time he gets something stupid, maybe a little teddy.
....and this was just one of the presents he brought me, stupid presents.
And I carry that snowman everywhere (*K p8-9*)

Growth

All of the mothers described the painful and debilitating experience of grief after the death of their child and the huge impact on their life, relationships, view of the world and others. However, each participant also spoke and reflected upon the changes in self and the quality of their lives since the death of their child. I have used the term "growth" to reflect upon the positive changes that such an experience can sometimes manifest.

View of the world/attitude to life

... things that were trivial before,
just don't seem to bear thinking about before.
Totally different perspective on life now.
That life is quite simple really and we only complicate it,
through evolution. (*A p11*)

..and to do some of the things I have done has amazed me.
I am happy that I can say to people that I have found a quality of life
That I didn't believe would ever be possible and
I am contented with that life. (*E p11*)

View of people

... I have a great freedom...
And I am a simple person,
..and when people complicate things,
complicate them quite unnecessarily. (*A p12*)

I find I have got a better level of understanding with people,
..it's like I have just got a different dimension to my life. (*J p12*)

The niceness of children,
..I am aware of that, people not treating children as they should.
If I see that, that upsets me really bad,
"you don't know how lucky you are." (*K p10*)

Self

In the earlier stages of grief some described a loss of self and need to search for, find or recreate self. Later, significant changes were described about how a new understanding of self developed, resulting in being able to express their needs more openly and knowing what was now important for them in their life.

I enjoy every minute of my life, every minute of the day,
So I feel as though I have got that pleasure in life again.
And to be actually able to say, confidently what my need is..
I feel I have got to know myself now. (*A p9*)

And this joy I say I have had over the last couple of years,
the new me that has emerged out of this.
Like a caterpillar out of it's cocoon.
Like a butterfly.

My whole life changed, my attitude to life.
... I think it gave me a thirst for a different life. (*A p11*)

My life is far more richer, more fulfilled,
I know what's important in my life.
I believe it has given me a level of understanding
and a level of sensitivity that I didn't have prior. (*J p9*)

but that person had gone.
And I thought, "I have got to find me,
I have got to find somebody I can live with.
I just need to find some level in which I can be at peace with me. (*K p7*)

If anything really upsets me, I have to say,
whether it is right or wrong.

I am quite placid now. ...
I am more assertive about what I believe in *K p10*

I am less tolerant of somebody who moans....
..and I think I listen more.
I am aware of what people are saying. (*H p9*)

I notice things more.
And I enjoy watching the young kids having a good time,
.... "they look lovely, they are bright and enjoying life"
I can see something nice in everything. (*H p10*)

You know I am contented with my life here,
I know C would be proud of me, which makes me rather content.
I probably give more of me now than I ever did.
Maybe I need to show people that you can really get through these things.
Whatever life throws at you..
that you can actually come through it. (*E p10*)

Living with the joy and pain

..bittersweet really.
Basically the bitter; you lose a child to suddenly find
You life has been enriched by loads of new people. *E p8*)

I'm comfortable now.
....because when you get to the stage where you are OK with it,
and you do get a bad day, it's nice.
They are still there,
they can still hurt you,
you can still feel the love."
... you actually feel OK with it because they haven't gone.
They haven't disappeared.

I hope I never get to the stage where he is fully forgotten. (*H p11-12*)

I wish, probably,
that I could have two sons,
like you,
healthy children who grew up and we didn't have to experience this.
But, I am not going to let that destroy me,
the fact that that didn't happen to us. (*J p12*)

My life's never going to be the same,
but I wanted the relationship back that I had with them (children).
..those magic times, you know?
They are quite hard to find again afterwards.
And they do happen, in time they will happen.

I say, he (grandson) made the sunshine again for me.
He made me laugh..
They (grandchildren) have brought me back. (K p9)

Positive changes

I am quite appreciative of the ups and downs of the life I have had
....because I can see through it an awful lot of good that has come out of it. (A p11)

I think I have learned and I have realised that you can grow,
you can move on.... (E p8)

C has given me the strength to look at the positives out of it and ignore the negatives.
But, I don't think that's me, that's him working with me. (J p12)

Table showing overview of themes and subheadings emerging within outcomes

Grief	Emptiness	Suicidal thoughts	Physiology	Sleep	Withdrawing	Anger
Relationships	Partner	Coping	Intimacy	Family and others	Children	Reconnecting
Memories and Images	Dreams	Images	Senses			
What Helped	Bereavement Centre and other bereaved parents	Reconnecting and re-engaging	Interests	Finding purpose	Nature and Landscape	
Creativity						
Beliefs: world, future and existential	Spirituality	Beliefs and meanings about death				
Continuing the relationship with the child, the bond	Continuing the connection and relationship	Linking objects	Conversations	Rituals	Gifts	
Growth: View of the world/attitude to life	View of people	Self	Living with joy and pain	Positive changes		

Discussion

'Truth is found in the midst of struggle and destiny.'
(Tillich, 1967)

I have structured the discussion by following the themes of the outcomes and grounding the discussion in the data and literature.

The bereaved mothers who took part in this research described their grief and the feelings of emptiness, isolation, anger and depression (Jiong et al, 2002) which they experienced.

Three of the mothers talked about processing their grief through dreams and images, which offered comfort at times and also enabled their loss to be expressed. Some spoke of experiencing depression, of not wanting to continue with their lives and sometimes of suicidal thoughts. The intensity of their grief impacted upon functioning such as sleep and sexual interest and some experienced physiological symptoms as the grief was expressed in their bodies (Hentz, 2002). In a study investigating the emotional consequences for parents following the death of their child Znoj & Keller (2002) found that bereaved mothers reported higher depression scores and deterioration in physical health than fathers and this was reflected upon within the outcomes of the bereaved mothers interviewed.

Whilst the participants experienced their grief in stages or phases it was clear that these stages were not necessarily sequential and in fact were revisited at significant times in theirs and their child's lives. The dual process model (Stoebe and Schutt, 1999) describes a dynamic alternation between focusing and avoiding the focus on the loss of the person, and this was necessary for some of the bereaved mothers interviewed, to manage their lives. Some displayed complex grief reactions and high levels of emotional distress intermittently for many years. The findings of a study by Ginzburg et al. (2002) revealed

that complex grief reactions are more prevalent in bereaved parents, particularly those who lost an adult child. However the findings of my research suggests that complex reactions are not specifically related to the age of the child, as the bereaved mothers in this study lost children between the age of 9 months and 24 years of age.

For the bereaved mothers in this study the intensity of grief resulted in a “shutting down” (*Janet p4*), a lack of connectedness with others (*Helen p6*), withdrawal from their life and relationships, and for all of the participants a deep need to stay in their grief before they could move forward. These experiences can further create a sense of failure and inadequacy that further compounds grief (Tonkin, 1998); “I didn’t want them to see me as weak as I was” (*Elizabeth p3*). In a study exploring parental bereavement and the crisis of meaning experienced, Wheeler (2001, p 62) found that bereaved parents reported experiencing a “shattering of their assumptive world that produced intense emotional turmoil”. The mothers in this study also described a crisis of meaning for many years (Lauterbach, 1994; Riches, 2002) and a search for self before they could then rebuild a new life. Parental grief for many is a permanent condition, and the child and their death is always in conscious awareness for many (Klass, 1999; Talbot, 2002; Tedeschi & Calhoun, 2004). The outcomes of this research are consistent with the current literature and research available on grief and child death.

Relationships were profoundly affected as a result of the mothers’ grief and the subsequent feelings of isolation. The loss and trauma changes the individual and their identity and the burden of a child’s death can add to underlying relationship problems. The differing grieving patterns in each partner can present problems in the relationship (Klass, 1998; Riches, 2002; Shirley, Murphy & Clarke Johnson, 2003). Kamm &

Vandenberg (2001) examined grief reaction and marital satisfaction in bereaved parents and results suggested a complex relationship between the two. This is consistent with the findings of this research: one of the mothers described how her relationship had ended: “by then we had split, by then we were well apart” (*Elizabeth*), and others struggled to manage their relationships initially and had communication problems, while some offered protection and support to each other (Rubin, 1993). The relationships with surviving children and friends were also affected. Most of the participants reflected upon the withdrawal from significant relationships whilst they experienced their grief. Whilst one mother found she became closer to her partner, and felt the need for intimacy and closeness, most described the difficulty they experienced with sexual intimacy with their partner, and the differences in how they coped with grief within their relationship. Withdrawal seemed necessary to enable them to make sense of their loss and only then could they reconnect and re-engage in relationships after a time of reflection and isolation. This was one of the most difficult aspects of the grieving for the participants, resulting in a sense of guilt and failure at their inability to be there for their family and friends; “I didn’t want to look at my daughters, I couldn’t handle their hurt” (*Helen, p7*). However it is not surprising, given the challenging and shattering of world-view, social, spiritual and existential beliefs, that relationships are challenged (Klass, 1998).

Participants reflected upon what helped and helps in their lives in enabling life to be continued. All are bereaved parent volunteers at a Bereavement Centre and they spoke of how the network of support, from other bereaved parents, was invaluable. Grief may be normalised through identification and empathy within the context of a group (Geron, Ginsburg & Solomon, 2003; Klass, 1997); “I just knew I needed to be with somebody else who felt like me” (*Janet, p8*). Reconnection and re-engaging in life involved

beginning to let people back into their lives and also taking up past or new interests. Some described significant life changes and re-ordering of what was now important in their lives. Creativity through writing, poetry, gardening and landscape was something that most participants described as helpful, particularly in the earlier stages of their grief. A growing volume of research now supports the conclusion that writing can have substantial positive implications for emotional and physical health, as a means of expressing, communicating and processing the trauma and associated feelings (Neimeyer, 1999; Gilbert, 2002; Riches & Dawson, 1996).

Another theme which emerged for most of the participants was how walking and solitary reflection enabled space to connect with self and the world through nature.

“I just felt at peace. I was free from the vice, I was me” (*Angela, p10*). Being amongst nature gave space to thoughts and feelings about self, the world and life and some spoke of how they re-ordered and refined their priorities and values for the present and future. This led to exploration and search for some of spiritual and existential meanings. Significant changes in self were described; an initial sense of loss of self, and need to search for, find or recreate self. “I have got to find me, I just need to find some level in which I can be at peace with me” (*Kate, p7*).

In a descriptive qualitative study (Wheeler, 2000, p.62) bereaved parents “reported experiencing a shattering of their assumptive world that produced intense emotional turmoil”. The death of a child can create an existential crisis; a search to make sense of the death and to find and explore existential realities, benefit or life meaning (Talbot, 2002; Wheeler, 2001; Neimeyer, Prigerson & Davies, 2002; Madison, 2005). “It’s caused me not only to reflect on the life and death of C, but the life and death of my own life

really” (*Angela, p11*). Some of the participants explored their view of death and the meaning of life and death. This can be both a positive and negative experience, and participants talked about how their views had changed as a result of their child’s life and death. Individuals who face trauma may be more likely to become sensitively aware and cognitively engaged with fundamental existential questions about death and therefore the meaning and purpose of life (Tedeschi & Calhoun, 2004). Some research has also been carried out into the connection between psychological and religious coping strategies of mothers who are bereaved by the sudden death of a child (Anderson, Marwitt & Vandenberg, 2005).

Continuing their relationship and bond with the child who had died was important for all of the participants. “We don’t stop talking about her” (*Elizabeth, p7*), “keeping talking about him” (*Janet, p9*), “he is there with me on holiday” (*Kate, p8*). Current theory is emerging, which encourages the maintenance of continued bonds with the deceased and renegotiating the meaning of the loss over time and integrating the memory of the deceased in their ongoing lives (Klass, Silverman & Nickman, 1996; Bonano & Kaltman, 1999; Neimeyer, 1999; Tdeschi & Calhoun, 2004; Talbot, 2002). In a recent study Ginsburg et al. (2002) concluded that many bereaved parents remain involved with their relationships with the deceased and these reactions should not be labeled as abnormal. In the past continuing of such bonds would be considered pathological or indeed poor adjustment in grief; however all five mothers were engaged in very active family, social and working lives. All had good engagement with life and included their child who had died in the here and now by having conversations about them and with them, keeping their memory and love alive, using their name regularly, linking special objects or rituals with the child, buying gifts for them (Wheeler, 2001) and not closing off that important

part of their life. It may be that there are arguments for bereaved mothers and parents to sever the bond and not continue a relationship. Perhaps for some that is needed to move forward and manage their lives, but as such this research has not been done (Klass, 2006). In the case of all five mothers I interviewed, the bond continuing was absolutely necessary to them, and indeed very healthy. All actively continued their relationship with their dead child alongside having coping strategies, time out and healthy active lives. One mother had spoken of how she experienced a sense of her child's presence soon after he had died: "I just knew he was there" and how that had offered her comfort; "it has been a comfort, a great comfort to me" (*Janet, p5*). Flatteau Taylor (2005) stated that focus on sense of presence is an overlooked area of exploration in counselling bereaved people.

Another theme, which emerged strongly with all of the mothers, was that of searching for meaning in their life after the death of their child: "I needed to find something that would give me inner peace" (*Kate, p7*). Kagan (1998) describes the turning point in the bereavement process as when the parent identifies a reason, passion or focus in their new life. All mothers spoke of finding this, whether through family, friends, re-engagement with life, nature, or through new interests and connections, "reengaging in life.... picking up the peaces of the life I had" (*Angela p7*). Klass (1998) spoke of the resolution of the disequilibria coming after the death of a child, into an establishment of a new self within a changed world. All of the mothers spoke of a search for a sense of self and needing to find a way of integrating the person they are now in the world changed by their experience of their child's death. They described significant changes in self and a heightened awareness of their own needs and life priorities. For some a deeper valuing of life and relationships developed (Murphy & Clarke Johnson, 2003) and in fact at times a new sense of positive outlook on life and appreciation of daily pleasures was reflected

upon: “my life is far more richer, far more fulfilled” (*Janet, p9*). This could be seen as post-traumatic growth arising after a period of restructuring and rumination (Linley & Joseph, 2002; Neimeyer, 2004; Calhoun & Tedeschi, 1998, 2002).

Literature, philosophy and art have for centuries explored the idea that there can be personal growth or gain through suffering. Heightened existential awareness has been explored resulting in the perspective that confronting illness, suffering and death, may lead to pronounced positive psychological changes (Frankl, 1963; Yalom & Lieberman, 1991). Etty Hillesum died in Auschwitz Concentration Camp on 30th November 1943, and one of her entries into her diary was:

*Living and dying, sorrow and joy,
the blisters on my feet and jasmine behind the house,
the persecution, the unspeakable horrors – it is all as one in me
and I accept it all as one mighty whole and begin to grasp it better if only for myself,
without being able to explain to anyone else how it all hangs together.*

Research into Post-traumatic Growth and the understanding that growth may occur in those who suffer a crisis is in its infancy (DeBrule & Range, 2002). New models of grief and trauma are highlighting the increased appreciation of the possibility of life-enhancing spirituality and post-traumatic growth that often follows in the wake of great adversity (Neimeyer, 1999, 2003, 2004; Linley, 2002; Linley & Joseph, 2004, 2005; Tedeschi & Calhoun, 2004). This has been referred to as “growth through adversity” or “adversarial growth” and “positive psychology” (Joseph & Linley, 2005, p 262). People intrinsically actualize and are motivated to survive and rebuild, and the organismic valuing process will lead to self-actualization and possible positive changes in psychological well-being. DeBrule & Range (2002) term this “The Silver Lining Crisis” suggesting that self-enhancement may follow a crisis and leave an individual stronger and more developed and with a higher level of functioning than before the event. Participants describe a

“totally different perspective on life now” (*Angela, p11*), “and to do some of the things I have done has amazed me” (*Elizabeth, p11*); “I have just got a different dimension to my life now” (*Janet p12*), and “I am more assertive about what I believe in” (*Kate, p10*). The findings of this research are consistent with current and emerging theory on post-traumatic growth.

In the past theories of growth have been descriptive rather than explanatory. They have not provided an account of the process of growth and it is not known why some people who have experienced trauma are enabled to experience growth, whilst others remain traumatized and suffer post-traumatic stress, depression and anxiety (Joseph & Linley (2005).

From the research I have carried out with the bereaved mothers the outcomes suggest that you can experience the negative responses alongside the positive.

*The deeper that sorrow carves into your being,
The more joy you can contain.
Is not the cup that holds your wine
The very cup that was burned in the potters oven.*

(Kahlil Gibran – The Prophet, 1923)

The assumption that trauma always results in disorder, should not be replaced with expectations that growth is inevitable either (Tedeschi & Calhoun, 2004). One of the strongest themes which emerged was the need to hold and express both the pain of loss and the joy experienced together. Many reported the increased feeling of the vulnerability of self and others coming out of the experience, along with an increased sense of their capacity and strength to survive (Calhoun & Tedeschi, 1999).

“Bittersweet really” (*Elizabeth, p8*); “I am appreciative of the ups and downs of the life I have had because I can see through it an awful lot of good that has come out of it”

(*Angela, p11*). Bereaved parents do perceive benefits from their endeavours to cope with the loss of child (Wheeler, 1994; Polatinsky & Esprey, 2000). In a recent study Barbero & Linley (2006) found that women tended to report higher levels of post-traumatic growth than men. In a study into the gender differences in the perceptions of benefits after the loss of a child (Polantinsky & Esprey, 2000), whilst mothers scored higher on the Post-traumatic Growth Inventory Scale, the scores did not reach a statistically significant level. Women tend to engage in a wider social network and are more likely to reach out for support than men; they are socially more inclined to share with others and communicate feelings. Men can often grieve privately and isolate themselves. Whilst mothers describe their grief as more public, fathers often describe their grief as a more private matter (Klass, 1998). “Three years later he collapsed.... Men do this ‘I’m ok routine’ and ‘I’m holding everything together’ ”. (*Janet, p7*) “He seemed to me to be coping very well. He wasn’t, when we finally talked about it, He wasn’t coping very well at all.” (*Kate, p5*).

Trauma and growth are on a continuum and perhaps using the term “disorder” to describe what one could argue is a natural response to a disordered experience is not helpful. Joseph and Williams (2005, p433) believe that “the mechanisms underlying the development of post-traumatic stress could be understood as normal, rather than abnormal processes”.

Conclusion

The death of a child is one of the greatest losses a human being can experience. It can leave parents and families devastated for many years, and the ongoing reality is of the child's absence throughout the remaining years of their lives. Poignant and significant milestones, which the child would have had, are constant reminders of the loss of someone precious.

The outcomes of this research support recent grief theory, and also what has emerged is the process of growth and changed values, which many described. Whilst the bereaved mothers experience intense grief, which can be revisited at different and sometimes significant times throughout their lives, they also shared a new perspective, attitude and experiencing of life and the world. This included a changed view and altered level of understanding and valuing of people. Many significant changes in self were reported such as changes in: attitude, enthusiasm for living, pride in self, contentment, strength and self-confidence. Some described feeling more comfortable with self and of experiencing a new sense of enrichment, joy and pleasure. However the growth that all participants describe is accompanied with an ongoing acceptance of the sadness and loss of their child "bittersweet", "they can still hurt you", he will "never be forgotten", "I believe he works with me". For the mothers who I interviewed post-traumatic growth has come alongside an ongoing relationship with the child who died, and with the pain of the loss of that child being integrated openly into their lives.

All of the mothers interviewed had been bereaved of their children for a minimum of 9 years, and it could be argued that these experiences would be more likely to happen after a longer period of grief. Other studies have found a possible, although not significant,

relationship between the length of time since the loss and the perception of benefit (Polatinsky & Esprey, 2000; Wheeler, 1994) whereas some research has found that positive changes were unrelated to the passage of time (Tedeschi & Calhoun, 1996). Therefore growth may not have been as evident had I had interviewed recently bereaved parents, and perhaps such experiences arise after a significant number of years of grieving. The interviews were retrospective, which for ethical reasons they needed to be; however it may be argued that such retrospective reports could be subject to potential cognitive biases, although there is research that indicates such reports are generally reliable (Barbero & Linley, 2006). There is an inevitable overlap of the themes within the data analysis and outcomes and another researcher analyzing the data might come up with different themes.

What is still to be discovered is what predicts growth in some and not in others, whether these outcomes would be similar in other social and cultural groups, and also why women report higher levels of traumatic response, depression, anxiety and subsequent growth than men. A joint study on both would be really helpful.

I hope that this research and the stories of the participants help to inform practitioners, researchers, academics and teachers of counselling, psychology, and nursing about the experience of grief, and further enhances the current emerging theory on 'continuing bonds' and 'post-traumatic growth'.

Epilogue

This research dissertation was required to go through COREC. www.corec.org.uk

Central Office for **NHS**
Research Ethics Committees
COREC

This delayed the research considerably. At the time it felt a frustrating and rather lengthy process, with a 52 page document to write and rigorous ethics meetings and committees to attend where the research was questioned and challenged. However, it also enabled a longer period of incubation, which I feel had a very beneficial impact upon the heuristic process. I was able to dwell and immerse within the data, and really consider many aspects of the literature and the focus of the study, whilst waiting for the positive decision to go ahead with the interviews.

Prior to beginning the interview process my mum died suddenly and unexpectedly at the age of 70. For me this was a very sad and painful time and triggered many memories of Sam's death. For this reason I needed space to reflect and begin my grieving for mum, and check out my readiness to safely and ethically begin the interviews.

I spent a long time on the transcribing process. Each taped interview I transcribed in two stages. One verbatim, and then one in narrative stanza format, where I was drawing out the meaningful data from the original interview transcripts. By putting the narratives into a stanza format it further enabled me to see another perspective and view of the participants' stories. This process actually was the most profound for me. I needed space to respond and connect with each story, each participant and their child who had died too. It felt at times painful and moving; I needed to look after myself and increased my

exercise and yoga to maintain self-care. It also however, offered a sense of hope, joy and inspiration to me. And whilst some days I would feel raw and emotionally moved, other days I would feel a sense of human courage and inspiration.

I began the research by engaging in my story first of all, and then focussing on each participant's story. I found that I was driven to complete this research as a sense of commitment to the participants and their profound stories, and also out of respect and duty to their sharing of self. One of my main struggles has been leaving the narratives out of the research. For me it felt important that these stories should be included, even if they exist within the appendix or an additional document alongside the dissertation. Having sat with these women and experienced the trust and offering of such incredible journeys it would feel disrespectful and indeed disregarding to remove the whole for the purpose of a piece of research.

As a bereaved mother this research dissertation has taken many years to decide to do. I had to consider fully my motives, ability and also readiness to work with an experience so close to my own life. I knew that ethically I needed to be able to be able to manage this for the participants but also for myself. I believe now, on reflection, having completed this research that not only was I able and ready, but also the bereaved mothers who I interviewed stated that it was helpful that I was a bereaved mother as well as a researcher.

As I write the conclusion to this dissertation, my husband and I have just taken our eldest son Tom to university. A time for celebration as he has achieved his A levels and entered into the next exciting phase of his life. We are very proud of our eldest son and what he

has achieved after such an early loss in his life when he was only seven. He is a lovely young man and on returning home we cried because he is no longer at home.

But we were both shocked that once again we were reminded of coming home without Sam, after he had died. Sam should have been 17 in December, celebrating his GCSE results this year and this would have been the time we had him at home alone for two years before his journey into Higher Education or employment, whilst his big brother ventured into independence. Being a bereaved parent is continual and ongoing and there is no time limit to that grieving process.

I would like to end my epilogue and dissertation with another diary entry from 1995/6. I began the dissertation describing my grief and will end describing the little boy whose life and death led to me carrying out this study; our youngest son Sam, Tom's little brother.

Sam

Such a lovely, loving little boy.
He enjoyed everything
and always showed his happiness.
He moved with enthusiasm,
danced, sang, kissed, loved,
told you he loved you over and over again.
He always made sure that you knew
how much he'd enjoyed something.
Thanking you for everything...

He would always make sure
he saw me go from school.
He had to give me a last
"kiss and a love mummy"
and see me off every time.
And if he didn't he'd chase me.
He'd hold you so tight
and count to five,
then ten,
then more,
as though it would be his last hug.
Oh how I miss his little arms around my neck,
So tight I could hardly breathe.

Diary entry, 19th November 1995

....and Sam will always be
a boisterous, inquiring, chatty
and loving five and a half year old.
With fine blonde hair,
and baby teeth
and fingers that dance around your neck
and through your hair,
and lips that seek kisses constantly
and speak of love daily.

Diary entry, 18th July 1996

XXX

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Appendices

Appendix i

Information Sheet for Research Participants

Study Title: A Child's Death – A Heuristic Exploration of Mothers' Grief

A study being undertaken as part of MA Counselling research by:
Gail Ashton who is a bereaved mother.

What is the study about?

I want to explore the experience of bereaved mothers following the death of their child, by examining their grief experience and looking at how life was before and after their loss.

The research will seek to reflect the depth of experience of bereaved mothers in a creative and thoughtful way. Participants will be asked to share their experiences through interview, and by sharing other creative means of expression they may have used, such as drawings, paintings, poetry, music, dance or any hobbies they may have.

Who will be asked to participate?

I am seeking to recruit 4-6 mothers who have experienced the death of a child aged between 1 and 21, and who are currently bereaved parent volunteers with the *****. It is appreciated that all of those approached may not wish to be involved in research, or may have no previous experience of expression though creative arts or writing. Only those, therefore, who express an interest, following an initial conversation with myself, will be invited to undertake further consideration to establish suitability for inclusion in the research project.

The first 6 people interviewed who fit the required criteria will be invited to participate.

What does it involve?

Participants will be interviewed by myself and invited to submit examples of any creative work they have done as part of the bereavement process. They will also be invited to do a piece of writing. The interviews will be sound recorded and transcribed into written documents. The recordings will be destroyed once the contents have been transcribed. Participants will be required to attend interviews at the *****. All interviews will be one-to-one with myself. There will be one initial meeting with myself followed by a taped interview of approximately 1-2 hours. There will be a follow up meeting for the participants to check the accuracy of the transcribed interviews and to decide if they are satisfied with the content.

Creative Materials / Data

As part of this research dissertation participants will be invited to share and include creative materials, which have been produced during the period since their child's death, and whilst participating in the research. These may include; poetry, narrative, diary entries, crafts, paintings, drawings and other visual materials produced by the participant. These materials will be included in the research dissertation as part of the data.

How will these materials be used?

This creative data may be photographed or transcribed and included in the research dissertation, which will be held for public access at University College Chester and also

at the *****. They may also be used in the future for: training materials, journal articles, articles, publications, CD's, lectures, presentations, books etc.

What will happen to the original materials

If possible your materials will be photographed or photocopied in your presence and not taken away by the researcher.

If they need to be taken away for reproduction, your original materials will be returned to you once they have been copied or transcribed. These materials are your personal and intimate property, and will be treated with complete respect and confidentiality by the researcher.

How will the research be used

The transcript and any creative materials connected with the research may be seen by Counselling Tutors and the External Examiner for the purpose of assessment and moderation. These people are bound by the British Association for Counselling and Psychotherapy Ethical Framework for Good Practice in Counselling and Psychotherapy. Copies of the dissertation will be held in the University College Chester Library and the Department of Social and Communication Studies Resource Room.

Some of the material may be used for publication and/or presentations at conferences and seminars in the future.

What are the risks of taking part?

It is possible that participants may find the process of recalling their experiences distressing or stressful. Support will be available at the Alder Centre if needed.

What are the benefits of taking part?

There are no direct benefits to participants. However the results of this research may benefit bereaved mothers and parents in the future and practitioners working in the area of bereavement and child death. It may also have implications for future research and understanding.

Will information collected be confidential?

Yes. All records will be anonymised so that participants cannot be identified from the reported data. Of course we cannot guarantee complete anonymity because it is possible that someone may identify you from having previously seen or known your creative materials (e.g. by having seen your artwork or poetry).

Are those approached expected to take part in the study?

No. They can refuse to take part without offering any explanation. Furthermore, those who do agree to take part can withdraw from the study at any time without offering an explanation. This decision will be respected and supported by the researcher and the *****.

Where can further information be received?

Those who require further information can contact me by leaving a message at the ***** so I can back to them, or by emailing me directly.

Name of centre***** Email: ***** Version 2, 7th June 2005

Appendix ii

Email g.ashton@
Telephone number

Dear

I am an MA Counselling Researcher, and my research dissertation is a study of the experience of bereaved mothers after the death of their child.

The study has ethical approval from the * * (NHS Hospital) Research Ethics Committee.

I attach an information sheet, which explains in more detail the study and some of the areas in which I am interested in researching.

I am also enclosing the broad themes that I will be including in the interview so that you have a clearer idea of the content, to enable you to understand the nature of the research.

I am happy to have initial meetings to enable you to ask any questions and to explain more fully the nature of the research and to offer you the opportunity to talk to me about this research.

My research will be academically supervised.

Your confidentiality and anonymity will be treated with the highest regard throughout this study.

Thank you for your interest,

Yours sincerely,

Gail Ashton
MA Researcher and BACP Accredited Counsellor

Appendix iii

Interview Structure

Broad themes and more detailed questions, which formed the structure of the interview. These were used as a guide to inform the interview process.

❑ Would you like to tell me about your child?

❑ How grief affected/affects your day to day life

How did your grief affect you in your day-to-day life, in carrying out your usual activities (impact on health too)?

❑ Memories and images

How do you experience memories of your child's life and death? (Thoughts, images, pictures, special dreams,)

❑ Relationships with family members, friends and colleagues

Can you tell me something about how your grief affected your contact with people, relationships and social/working life?

❑ What helped?

What would have helped? What was missing?

Can you describe any things that enabled you to cope with your grief – ideas for others.

Self-help. Were there any things that you were able to do for yourself that helped you with your grief.

❑ Creativity

Have you used any creative means to express your grief such as: painting, diaries, poetry, music, sewing, etc.?

Did you take up any new hobbies or interests?

❑ Thoughts about self, and future (Existential)

What thoughts and beliefs (eg spiritual) did/do you have about life, your future and the lives of those that you are close to after your child died?

❑ How do you continue your relationship with your child who died?

Talking, writing, thinking, job, roles etc.

❑ Growth

Are there any things, which are now different and positive and/or negative in your life, which have come out of the change in your life since your child died?

❑ Anything else you wish to discuss

RESEARCH CONSENT FORM

Title of study: A child’s Death - A Heuristic Exploration of Mother’s Grief

Name of Investigator: Gail Christina Ashton

Name of Participant:

- I confirm that the above study has been fully explained to me ☐
- I confirm that an information sheet was provided which outlined the details of this research and I was given the opportunity for further explanation by the investigator ☐
- I believe that I have been given sufficient information about the nature of this research to give my informed consent to participate ☐

Participation in this study is entirely voluntary and there is a right to withdraw from the study without giving a reason or explanation, at any point in the investigation.

Signature of participant.....

Signed in the presence of
As witness to the above signature. (please print)

Signature of witness..... Date.....

Job title and department if member of staff.....

Address if unconnected with the hospital.....

..... Post Code.....

Appendix v

Elizabeth

Although I find it very difficult to talk
I want you to know this is not because I don't trust your love for me
I want to say
"I don't seem to be able to find peace of mind
In sleep I do
In sleep I am closer to C
But sleep doesn't come easy
How can I say how much I hurt
Hurt is in my heart
At the moment I feel that never before has anyone person felt so much pain
But, also I know there have been people before
And there will be people after me
My feelings are very selfish
In my heart I know she was P's child too
She was my parents' and his parents' grandchild
Please don't think I don't know the hurt and pain they are also feeling
But in my grief I am an individual
My grief is personal to me
And at the time of writing this
I am only expressing my own feelings
I say my feelings are selfish feelings because every day I ask God
Why!
And I ask him to send her back to me
Then I get confused because should I ask for her back
Knowing she was so ill
The answer of course is always YES
I just want her back to hold to talk with
I want her BACK

The tears just flow
I think of something
See something
Hear a song
I still have to respect other people's feelings
but its not always convenient for me to talk
and then the moment has passed

I have no incentive to do anything or go anywhere
I want more than anything to just stay here in C's room
Surrounded by her things
I could throw away the key and stay and maybe
C would come for me
It's a futile thought
However I've realised I'm not frightened of death
It's the only time I've given it a thought

But at this pint it would come as a relief
In more rational moments I know I am blessed
With good family and friends
Who're sticking by me no matter how many walls I build up
And I appreciate all of them
But please try and read this – for me
C was contentment of my life
I loved her company
Now I feel no quality or contentment in my life
I have always been lucky enough to see the beauty of life
Now I can't write about it,
Photograph it
Or listen to music
Will it ever return

I hurt like hell and just sometimes
Someone gets the wrong end of my tongue
I would never intentionally hurt anyone
I'm sorry
Stay with me

Appendix vi

Elizabeth

C had Cystic Fibrosis and that's a fact
C did not suffer her illness and that's also a fact,
because she fought her illness every second of every minute of every hour of every day.

She fought her illness with all her strength, both spiritual and physical,
and when she died her spiritual strength was as strong as ever
but her physical strength failed her.

C's strength cam from the love of the people who surrounded her.
Her Church, family and friends,
And in fact anyone who knew her.
In return she touched each person she met with a special gift of happiness.

Many people will be hurt and suffering because C has left them,
and to them I offer this consolation
C is now with God,
who is the source of boundless love.
God' love will give us the strength as our love gave C the strength,
so if we pray to God through C he will answer our prayers and fill the void in our lives.
We should hold the memory of C in our hearts with pride and not with sorrow,
pride that God allowed us to know her
even if for a short time.

The day C stopped breathing was the day I stopped living.
That was six months ago, some things have changed since then,
And I want people to know about these changes,
Especially those who may be going through the same experience as me.

From the very moment of death,
the hurt I felt choked me beyond anything I have ever felt in my life.
I was very confused,
knowing I did not want my child to suffer,
not wanting her to leave me,
I wanted that miracle that we all pray for.
But it was not to be,
for me anyway.

Family and friends carry you through the first few weeks.
The hurt engulfing your whole self,
so you don't really know or realise that she won't be back.
No more smiles, no more hugs, just no more anything.
And can you cope with that?

Your first thoughts are that you don't even want to,
and then time has a way of passing while you're still thinking,

and you realise that you are coping the best way you can.
You realise close friends don't expect anything from you.
You don't have to be brave and fight your inner feelings.

I felt very inadequate in my grief.
I believe that one reason for this was because I was never a very religious person,
and I thought that because P was, that he could understand it all better than I could.
He had the same strength as C, whereas all I wanted to know was, WHY?

How could God do this? How could God make people suffer in this way?
I think all this came about because I couldn't or wouldn't accept C's death,
and so I argued with every explanation given to me,
and if I couldn't argue I just didn't want to know.

I was just giving in to everything
well what was the point
there was no posing to anything anymore.
C had gone and I was a physical and mental wreck.
My crying became uncontrollable, and again I felt very weak
and embarrassed at being in this position.
I refused help from friends, I shut them out.
It was my problem, not theirs, and how could they understand?

And yet, there they still stood, by me!
And here I was
alone with my grief,
and I think that's the most frightening part, alone.
I thought I was going mad and yes, to be honest, it I thought of ending it all,
because I was alone. But I was alone by choice, not a wise choice.

So, gradually, because of being afraid of being alone,
I started talking to P and friends, only to find that they need me to let them in.
They were loving and anxious to help, and I was glad.
From this I realised I could cope, maybe someday for just the odd hour or two,
But gradually that hour has grown into days and weeks, and now months.
Of course it is never as clear cut as we would like it,
and I still have very bad days, but fewer.

I still have to get over a lot of firsts, birthdays, school holidays,
places we visited as a family, and at the time of writing this,
Christmas is my biggest worry.
It's the end of October and I have been having a lot of upsets
seeing people preparing for Christmas,
and listening to other children talking about it.
I don't know how I'll get through it,
But what I do know is that I will, even if I cry from beginning to end,
but you see that doesn't matter anymore, I still come out the other end.

If you remember at the beginning I thought I couldn't cope because I wasn't religious

and didn't have that insight, but who have I talked with all the way through this,
Well C, but only with God's help can she get me through.
Because my friends loved her so much they have shown each in their own way
their love for me, and they are gradually restoring the balance in my life.
I now ask C to give them the strength to last the pace,
as without them I know I shouldn't want to go on.

Results so far? Talking about C happily,
remembering all the fun things about her,
knowing with her guidance I will one day recover from this,
and survive to be the person I once was.
In a way other things are beginning to fill the void,
Things I don't feel guilty about,
But things I know C would be proud of her mum doing.
And in a way although only six months on I believe she has brought me through
To the recovery stage,
But I make no excuse for slipping back sometimes.
I hope it will be a different story in twelve months time.

Angela

The spaces were open, the fields were bright
The darkness of heart seemed to fade into night
We gathered as one, in the games as we played
Laughing and squeaking as in days gone by.

We shared precious moments, sometimes shedding a tear
It's OK to do so, as friends we are here
Some of our children are living and some dead
But somehow our spirits are light years ahead.

They have not really left us. We know they are alive
As our hearts can't forget them, as their spirit lives on.

The pain and the suffering was it ever worthwhile?
Can we measure or judge it, is it really worthwhile?

So we danced and we sang, let our spirits go free,
Let go, don't hang on, that's not for me.
If only and why, has not answer for me
So I dance and I sing and I giggle with glee.
I've a child in my heart who wants to play and go free
Why stop him? Just let him be, as he lives on in me.

The good times, the bad times, are rolled into one
Confusion and depression, has got up and gone.

Oh, I love him, I love him, I will never forget how
He brought joy to my heart from the moment we met
And now that he's gone, his spirit lives on.

What will I say, when I meet him again?
I am sorry my love, what went wrong
I don't understand. I expected you to be strong.

I picked up your weakness, the burden I carried
But I try to live on, as I dance and I sing
And your spirit lives on.

Mum
XXXXXX
Angela 2003

Appendix viii

Helen

"I wrote it down", she said

I am in a deep dark hole,
I didn't fall in,
I put myself in.
I don't like it in here,
But I don't want to come out.
Nobody can touch me or approach me
with a silly look and the daft "ahh!"
I won't look at my husband's vacant eyes
or the deep hurt in my two daughters eyes.
Further down I go,
yes, I do like it,
you see I don't belong to anyone,
I don't need anyone,
I will always feel like this.
If I look up I see the heads against the light.
Just go away.
I wish they could understand.
I want to wallow in the pain, darkness and loneliness.
I hear the whispers
"she is depressed."
Hah! I wish that was I had,
medication would help me if I was.
I want my son back,
Can anyone help me?
NO!"

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Initial Engagement
This phase involves the researcher engaging in the task of discovering a subject, which is of intense interest, a passionate concern for the researcher and that also has wider important social meanings and personal, compelling implications.
Immersion
The immersion phase is when the researcher becomes intimate with the question and anything connected with the question and immerses in the experience of all aspects of the question. This phase involves self-dialogue, self-searching, focussing and concentration on the topic, possible meanings, and the pursuit of knowledge.
Incubation
In this phase the researcher retreats from the intense concentrated focus of the question. This period of incubation enables an inner level of awareness of the nature and meanings of the topic to emerge.
Illumination
The researcher is open and receptive to the tacit knowledge and intuition acquired in the previous stages. The researcher is reflective and open to new constituents of the experience, adding new dimensions of knowledge. Often in this stage, awareness or insights will emerge or appear, or something that has been missed will be illuminated, and add something essential to the research.
Explication
In this phase a more complete apprehension of the key ingredients is discovered. A comprehensive depiction of the core or dominant themes is developed. The researcher brings together discoveries of meaning and organises them in a comprehensive depiction of the essences of the experience. Explication of the major components of the phenomenon, in detail, and then putting them together into a whole experience.
Creative Synthesis
In the final phase the researcher is thoroughly familiar with all the data in its major constituents, qualities and themes and in the explication of the meanings and details of the experience as a whole. The researcher then puts the components and core themes into a creative synthesis. This is where the creative data is used to reflect the phenomenon. The researcher needs to move beyond any confined attention to the data itself and enable the question to grow to form a comprehensive and whole expression of the essences of the phenomenon investigated.

A child's death:

A heuristic exploration of mothers' grief

Gail Christina Ashton

The bereaved mothers' stories

Five bereaved mothers were interviewed as part of the study and their verbatim interview transcripts were adapted into stanza format for the purpose of the data analysis. Each individual's story is presented here, alongside the MA Research Dissertation.

The participant's narrative is in normal text and the researchers narrative is in italic.

Angela's Story

Beginning the story



C was with born with disabilities.

He lived 9 months,

he wasn't expected to live at all.

He was beautiful (smiles), he was really lovely.

To me he never looked Downs Syndrome in any way. He was blonde.

There were lots of traumas over the 9 months we were in and out of hospital, but it was a good time in a way because I had time to kind of educate student doctors in a way, because it was so rare in those days and they didn't have the knowledge they have now, you know 20 years on, there's much more knowledge of these kinds of disabilities.

They can do an awful lot more now for children now with this kind of condition, but then it was kind of a losing case really. (p 1)

C died in his operation,

and I remember the day so well, I really do.

And even the days preceding because three days before I spent in hospital with him, and it was a lovely time.

The family visiting,

the kids were there,

they were younger then and they were all there. (p 2)

The Bond

I knew what his needs were.

And I think that's with every mum and as a mum that's what brings us to the love and closeness of our children and that is why we grieve so much,

because I think when you have a child, you actually live in that child, you live in that child's life.

'That child is heart and soul, it is you really'

The bond.

The bond is there, it's heart and soul.

A baby can't speak for itself, it can think for itself.

Even a toddler relies on you 24 hours a day,

to meet all their needs,
you know, food, drink, clothes whatever, sickness, everything.
So when a child dies, when that goes, it is a very big part of you that goes. (p 1)

That goes with them.

How grief affected/affects your day-to-day life

Yes, yes, you get this empty feeling, an emptiness inside.
When that time comes,
no matter whether the cause of death is accident or sickness or disability,
whatever it is.

Whatever the cause of death

Whatever the cause of death you're still that mother,
you've carried that child,
nurtured it,
loved it from the day of conception.

So, it's like what can you do with that, huge space that is left?

Well exactly, there's all this emptiness (p 2)

I cried, I cried so much
I think my grieving process started the day he was born,
Because I was grieving for the pain of his disability. (p 4)

You live and breathe for your child,
it doesn't matter what your child dies of.
It is about a relationship between a mother and her child.
And that is why I like to speak for disability and particularly because the child here
is no different from any other child.

He is your son

It is this unconditional love, isn't it I suppose. (p 5)

I spent hours just wailing,
You were saying before how you wailed this terrible wail,
I was the same
And P just didn't know what to do for me
He couldn't feel my feelings,
He had his own feelings,
Obviously very deep, in a macho way.
Men do grieve differently, don't they? (p 6)

I did throw myself into the job because I am one of these people that if I do take something on I have to give 100% or nothing, so really I suppose, I went for burn out, basically.

So, you worked and worked and worked.

I worked and worked and worked,
and didn't give myself time to think at all. (p 7)

I felt ill really.
I can remember the pain inside me,
the physical pain and the mental pain,
and the tension in my head, and the migraines,
the headaches, they went on for years.
And probably because I didn't know what to do with this next lot of grief,
I just didn't know what to do with it

It just went into your body?

And it went into my body,
I am convinced it went into my body. (p 9)

I couldn't even explain how I felt. I just felt I was in a vice.
I can still wake up in the night feeling very, very tense.
I know I will never be the same. (p 10)
I could have slept my life away, really, basically.
The bed was the only place,
under the duvet, was the safest place I could be,
to be quite honest.
I was exhausted, yes,
I felt physically and mentally exhausted. (p 10)

I can remember running off to Taize.
I just wanted to be away!
I just wanted to be free,
I didn't want to know anything of the stuff I was leaving behind.

You wanted to be free of the vice like grip

I wanted to be free of the vice like grip mentally and physically. (p 11)
I just couldn't make sense of anything. (p 12)

I was waking up during the night and I didn't realise
that clinical depression had set in.
So these eight years all I was doing was running and running and running. (p 14)

It was like being in an empty room I suppose
It was awful, it was awful.
This was all part and parcel of grief,
this is all, as they say, grieving process.
Whatever grieving process means.
Does anyone ever understand grieving process? (p 15)

Only you can know what your experience is

I felt that pain had been so hard and so painful,
the pain of everything, that I couldn't risk it again.
And I wanted, I don't know if I wanted to stand alone,
but I was standing alone, whether I liked it or not.
I didn't like standing alone, but maybe I needed that time.
I just don't know?
And I was so depressed, I didn't want the phone to ring,
I didn't want to see anyone, I couldn't face anybody. (p 16)

Memories and images

I remember you were talking about dreams

Dreams and memories

I remember having a dream one night, early hours of the morning.
I don't know, it was a summer morning, and I woke up from the dream I'd had.
I'd dreamt I was at a party at one of the big manor houses on the cliffs.
And I looked for people, living and dead,
friends of mine and in particular one boy S who died when he was 33,
he had cancer and I was very close to his family and loved him very, very much.
And his dad was there, and we were all around.
And the only person who wasn't there was C.
And S's father came to me and he said "I've seen C, I know where he is".
And I said "He's dead" and he said "no, no, come with me, I know where he is".
And he took me by the hand, and out of this big building,
and we walked along the way to another house, a big mansion house.
And a woman opened the door and she had this child on her hip,
about 6, 7 years old at the time, he had big curly hair, and really bright looking.
And he said "here's C" and I said "ah, so it is". And so I said to the woman "do you
mind if I just take him?"

You knew it was him.

And she gave him me, and a big boy he was.
And I stuck him on my hip and I went "ooh"(gestures a huge hug/squeeze)

and I am cuddling him and ooh,
and I squeeze his cheeks and I am kissing him to pieces.
And so I say, "can I take him to show my husband?"
and she said, "that's ok but you've got to bring him back".
And I said "that's ok I don't mind, I'll bring him back, just let me take him to show P".

You knew you had to take him back

So I took him back to this place and a young woman who was dead,
late thirties, who had died of cancer that I knew,
and P was singing, because he loves singing.
And I said "look I have brought C".
And all these people came and we all embraced C,
and there were tears in P's eyes, and he said "you have to take him back".
And I said "I know".
And we just left and we went back to the house and we knocked on the door.
It was a big door, and when they opened the door it was like a big hall.
Lovely parquet floor and oak walls.
And I just put C down on the floor and he just walked down this hall, and off he went.
And I just felt this overwhelming love and happiness.

And the next thing I wake P up and say, "P, P, wake up,
I have got to tell you this now!" and then it all came out.

It actually gave you comfort.

It was like I had given C over there.

That you'd actually accepted where he was

I'd accepted, maybe I had accepted then, yes.

*That was one of the things I was going to ask you, memories, thoughts and images,
special dreams that you have had.
It sounds like that was a very profound dream.*

It was a very profound dream. And that was eight years on.

Relationships with family members, friends and colleagues

It was difficult to talk even to my husband P,
because he was very sensitive you know,
and very sensitive to me as a mother for that child and feeling my grief very,
very deeply, and he knew what I was finding very hard to express.
Almost trying to protect each other

Trying to protect each other all the time. (p 4)

I found my husband intolerable, I couldn't bare him touching me.

I can certainly remember that.

I just didn't know where I was, I didn't know what to do. (p 11)

As a wife, as a mother

I didn't know whether I wanted him, I didn't know whether I wanted to leave him.

You know, it was all part of the grief. (p 14)

I wanted him to understand how I felt, but he couldn't possibly understand.
I mean God love him, he is the most loving man you could ever wish to be with,
and so patient and so kind, but even his kindness was painful to me.

Nothing was helping

No, I couldn't even tolerate his kindness

*That kindness in a way at a time when you were feeling so raw was in fact contrasting too
sharply. So at that point what you didn't want?*

I suppose I was putting a barrier up really, I didn't want anybody to come anywhere near
me that could upset me again.

That could hurt you

That could hurt me. (p 16)

He was magnificent.
I am getting really emotional just talking about it now,
he was a rock for me.
I think you could say that. (p 20)

It's like the old saying "you only hurt the one you love"
and you trust that person so much you know you can beat them up.
I look at P as being my punch bag,
and now I just want to make him happy. (p 27)

And one of the things I remember more than anything my son who was then 17,
he was terrific you know.

And I was in bed one night, and I was crying,
and he said "mum what can I do, is there anything I can do for you?"
and I said "no son, I just want to hold a baby, I just want him here".

So he stood by my bed and he stripped down to his underpants

and he got in bed with me..
And I'll never forget it to the day I die,
and he got into bed with me and he got into the foetal position
and he put his backside into my stomach, a
nd put my arm round him and said "will I do mum?"
And we lay like that, and the pair of us just cried.

Because I just needed to hold a baby, and he was saying "I'll be a baby"
He was seventeen for god's sake,
you wouldn't expect that would you? (smiling)
from a seventeen year old, and he is very special our son. (page 6)

*It sounds like he knew what his mum needed?
And whilst you needed C he was saying 'look I am here'.*

I didn't want her to know what was going on, because you wore the mask.
Things went on but you'd wear the mask

So you were protecting

Always protecting people, not for myself, always for others. (p 14)

What helped?

To be together, to share..
We were sharing together the loss of our child.
So, we went for a walk and that night
all the mums and dads and kids all shared together.
To be together, to share, so for me the bereavement centre, it's just absolutely wonderful.
It's the most marvellous place on this earth as far as I am concerned.

It sounds like at that point it was like a gift for you?

It was. It was a gift. (p 8)

So they helped me as well to recover,
They helped me to share. (p 9)

Reengaging in life,
and starting to join in with the community that I had been involved with before,
that I had been isolated from for that eight years.
So I was beginning to pick up my roots again, if you like.

Picking up the pieces of your other life?

Pick up the pieces of the life I had.

And building on my self-worth.
Getting back in touch with others and getting in touch with myself.

And realising from that night when I ran away, realising, I want to be me. (p 21)

But since then I have carried on walking and I love the group I am with,
we go on holidays together and it's good fun.
They are lovely people to be with.

So, it brings you laughter and joy

Yes, it brings me laughter and joy (p 24)

Faith: And I managed to come through that through the grace of god. (p 26)

Creativity

Reflection on a therapeutic weekend in Wales

The spaces were open, the fields were bright
The darkness of heart seemed to fade into night
We gathered as one, in the games as we played
Laughing and squeaking as in days gone by.

We shared precious moments, sometimes shedding a tear
It's OK to do so, as friends we are here
Some of our children are living and some dead
But somehow our spirits are light years ahead.

They have not really left us. We know they are alive
As our hearts can't forget them, as their spirit lives on.

The pain and the suffering was it ever worthwhile?
Can we measure or judge it, is it really worthwhile?

So we danced and we sang, let our spirits go free,
Let go, don't hang on, that's not for me.
If only and why, has not answer for me
So I dance and I sing and I giggle with glee.
I've a child in my heart who wants to play and go free
Why stop him? Just let him be, as he lives on in me.

The good times, the bad times, are rolled into one
Confusion and depression, has got up and gone.

Oh, I love him, I love him, I will never forget how
He brought joy to my heart from the moment we met

And now that he's gone, his spirit lives on.

What will I say, when I meet him again?
I am sorry my love, what went wrong
I don't understand. I expected you to be strong.

I picked up your weakness, the burden I carried
But I try to live on, as I dance and I sing
And your spirit lives on.

Mum
XXXXXX
Angela 2003

Thoughts about self, and future (Existential, spiritual)

And when I was in the church I had this feeling,
I could feel this lovely yellow glow,
and I said to P, "we must go now, and get to the hospital."
A really strong feeling. And then she came out and she said, "we've just lost him". (p 3)

But what I felt I was searching for,
I was looking for joy.
Today, I feel very joyful,
I enjoy every minute of my life, every minute of the day,
whether I am doing nothing, something, whatever I am doing,
I feel it's a pleasure.
So I feel as though I have got that pleasure in life again.
It has taken me all those years.

It has been a real struggle for you to find it

To be able to touch it,
to be actually able to get pleasure out of life.
And to be actually able to say, confidently what my need is,
and feel happy about expressing my need....
And I can understand what my true feelings are.

So, almost like you really know yourself now?

I feel I have got to know myself now. Yes.

And it's taken a long time
And it's taken an awful long time

What a journey you have had Angela

It's been a horrendous journey, it really has been a horrendous journey.
So, now I am well connected with my friends, my family. (p 21)

I connect with my joy when I am walking.
I just knew that when I was on those mountains I was free and uninhibited about
anything,
I had no kind of particular emotions.
I just felt at peace.
I was free from the vice.
I was on those mountains, I was just out there and I was free.
I was me. (p 23)

Do you find that you have spiritual moments or real profound moments?



Like when I went to Taize and walked along this avenue of trees and I looked up,
and of course it was January and the trees were all dead,
and here's this lovely green growing on the dead tree.
And I looked up and I said "P, that looks like mistletoe."
Lovely mistletoe berries, you wouldn't see them here,
you know its dried up and doesn't look as vibrant as this looked.
And here was all this healthy green mistletoe growing on this dead tree,
it's like a fungus isn't it?
And so I saw this tree,
this dead tree
and I thought "well, this is the new life, this is new beginnings", you know?
"This is life coming out of death."

Are you the mistletoe Angela?

Yes, I think so, I am now the mistletoe.

The new life

The new life. (p 24)

How do you continue your relationship with your child who died?

(In the hospital just after C died saying to the nurse)
I remember kneeling down with her and saying,
“May C’s death be the life of another child” (p 3)

And I also believe that life goes on.
Because C is living on,
in the hearts of my children,
and my children’s children, my grandchildren.

So he continues

He continues on,
the love.(p 24)

I wanted to give what I could to my grandchildren in the way of spiritual,
psychological, to pass on something to them that will help them to grow in their lives.

Is that almost as a result of C?

Oh yes, I think it is all connected to him.
I think it all links in.
It’s all life and death experience or life coming out of death. (p 25)

In my daily life I say, yes, he is our angel in heaven.
C’s just inside of me.... Like I said, in there,
And I have this freedom to know that he lived,
To know that he died,
And to know that he is still part of our family. (p 25)

Growth

My whole life changed, my attitude to life.
It did give me, I think it gave me a thirst for a different life.
I wanted to understand what was happening with me I wanted to know what was going
on, I read loads of books, always books, for spiritual growth or books on health and
healing, looked for ways of improving myself, so look from within, nobody can do
anything for me.

There’s only me that can do this?

There must be something I can do for myself.(p 10)

I am quite appreciative of the ups and downs of the life I have had over the twenty years because I can see through it an awful lot of good that has come out of it. (p 26)

I am talking now as a 63 year old person, who lost a child 20 years ago,
and realising how it's caused me not only to reflect on the life and death of C,
but the life and death of my own life really.

Because I feel like I have been through life and death here on earth.
I feel like I have had life here on earth and I have experienced death, and I have
experienced the newness as well.

And this joy I say I have had over the last couple of years,
the new me that has emerged out of this.
Like a caterpillar coming out of nature, a caterpillar out of it's cocoon.
Like a butterfly.

So, you are ready to fly?

There was a time when I felt like a butterfly with a pebble on it's wing
and I was kept down there.

So, you've always felt the butterfly within you?

I felt the butterfly within me but I had a pebble on my wing but now I can fly. (p 27)

I think the thing that has happened now is that maybe things that were trivial before,
just don't seem to bear thinking about before.

Totally different perspective on life now.

That life is quite simple really and we only complicate it,
through evolution,
through things that happen in our lives.

We get tied up and we tie ourselves in knots unnecessarily really,
but it's the only thing you can do at the time,
because that's all you know at the time.

So it's only when the knots are unravelled that the string becomes straight if you like.
(Giggles) Can you walk on that line and not worry.

And know where you're going almost?

And know where you're going, yes.

I mean I can't say, I mean I don't think there is anything such thing as the perfect life,
and possibly in the future there'll still be more problems,
because that's life, and more heartaches.

I would hope I can look at them in a different perspective. (p 28)

I have a great freedom.

It sounds like you are a butterfly happy to be

I am just fluttering around, I am just fluttering in the breeze now.

What colour are you, have you got an image?

Yellow, fluttering in the breeze

Similar to your gold that you were talking about

And I am a simple person,
and complications,
when people complicate things,
complicate them quite unnecessarily.

So you like it straightforward?

I like it straightforward.
And sometimes complications come in
and there are some things you find hard to deal with.
But then I don't look for them. ...

Elizabeth's Story

Beginning the story

C was born with Cystic Fibrosis.
And then died in hospital in 1984.
And because she had Cystic Fibrosis she was someone
who needed certain things, like physiotherapy,
tablets, all the rest of it. So, every single thing at home
revolved around her as well.
And that wasn't a problem,
it was something that P and I loved doing.
We loved doing everything for her,
and she wasn't the sort of child who complained about having an illness,
she still did everything.
And it was our life, I suppose,
well, the three of us I think, were just the best of friends.
She took on a lot, from about eight.
And very sensible and very able, to do all of these things,
to understand her illness, which she did.
I was very proud of her really. (p 1)

How grief affected/affects your day to day life

Because C was our only child then the impact
was absolutely immense because every single thing I suppose
revolved around C.
She was absolutely everything to us.
And then, suddenly, one of the group had left,
and the void was immense,
and I actually felt very redundant.
If you live with all of that and that is removed,
You suddenly, even though you have an outside social life,
well, for what?
It didn't really feel much to be honest.

Even though you had all those things, like your sport, it was meaningless.

Yes, absolutely, I don't know why,
I had them before C, but then you do them as a unit.
So it was suddenly,
"well what's the point of doing all this?"
to be honest.
There was not point in it.

There was no joy in it.

There was no joy in it at all.

Did you stop those things? Were you able to carry on those things or not?

A lot later, A lot later I did. But straight after I just didn't.

Because if you walked on the golf course,

She should have been there.

If you walked into a tennis court,

She should have been there.

All reminders, so you had to pull yourself back from everything really.

Yes, I just didn't do it.

I didn't sleep much, for a long, long time.

I just wasn't tired, I just didn't sleep. (p 1)

Memories and images

The rest of the time I would say she probably occupied my thoughts.

And I could always remember her,

I could see her doing different things.

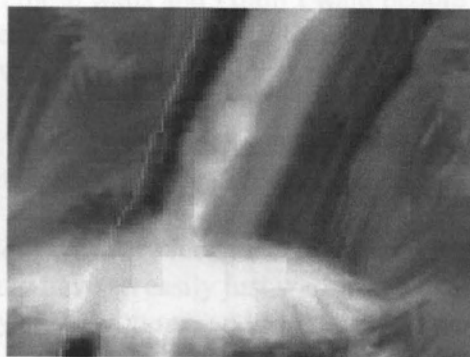
But just for one day I couldn't remember what she looked like.

I don't know if it was just a block or what,

But it did happen and it was horrible.

So, if you think of C, do you have symbols or things that connect you with her?

Things that might spark memories of her?



Many things.

Freesia, rainbows. Rainbows are our biggest connection.

Because just before C died,

She went out of the hospital on a shopping trip

and brought me a card,

which said

“rainbows are forever”,

because we would often walk the golf course and see rainbows,

and when we did certain things.
Sometimes you would look up and see a rainbow,
and she would always say "there's a rainbow".
And it connected us.
And whenever she drew a card, or drew anything for me,
She always drew a rainbow on it.
So, rainbows for me. (p 2)
On my birthday, the biggest rainbow came.

What does that mean for you, when you saw it on your birthday?

I honestly felt, she is actually thinking of me.(p 3)

Relationships with family members, friends and colleagues

I built walls,
and they couldn't cope with the way I was.
Because I just turned into myself.
I couldn't share how I felt,
because I didn't want them to see me as weak as I was.

Because you had always been quite strong?

Yes, and I couldn't cope with the fact they wanted to love and care for me.
And that's what they wanted to do and I couldn't cope with that because,
let's face it, in normal life that is what you really live for,
and that's what gets you through.
But I just built these walls and I didn't want people to see me weak.
I was embarrassed if I cried, I was apologising for it,
I was like apologised that I had lost a child.

*So, something about wanting it to be ok for you to be sad and weak.
You wanted space to do that and the only way you could was to keep yourself private.*

I probably did. I was very lucky that friends stayed around because
they could have so easily just walked away after so long
but they stuck with me, and I think I was lucky in that.

So, what you probably needed was there patience?

That's the right word really, I did.

And you know P and I were really close,
We had been married 27 years, and we were really good friends.
But, I could not be responsible for anybody but myself. (p 3)

It was enough to have to look after yourself

I just wanted to be Elizabeth again, I just wanted to be me.
I didn't want to be just P's wife, and that's because C had gone.
I wanted to be a mum, but I couldn't be.

I want to go back, for peace of mind, I want to go back to just being me.
C died in 1984 and so, in 1987 I just said to P,
really I had the worst years of being nobody

So really then it was just getting down to sorting out my personal life,
And obviously yes, my personal life was very personal.
It just had to be mine.

So, you had a very different way of grieving the two of you.

P, threw himself into his work, workaholic.
We went away to live in London for six months.
I just went along, that is it,
You just go along. (p 4)

And P was wonderful, don't get me wrong,
in all this there were never any arguments,
he did everything I wanted him to do,
And then he got an opportunity to go abroad,
And I said "I can't go,
I want to be here."

So, you actually needed familiarity.

Yes, I didn't need to run away.
And four years after that P came back and said
"I've made the biggest mistake of my life, help me"
because he said he just threw himself into work,
he thought that was what he needed.
He didn't know that you did need to talk to people.

And by that time your marriage was over.

By then we had split.
By then we were well apart.
Even in just our ways of thinking
and what we wanted out of life. (p 5)

What helped

The main thing that helped me cope with grief was setting up the bereavement centre.
And just basically knowing that we needed a bereavement centre
for people who would come after us.
Because we knew there would be people coming after us,
And there was no support and we wanted support for them.



At the time it was the garden.
At particular times, on anniversaries, birthdays and things to do with C
I bought Azaleas, because C like Azaleas.
I also went to * Gardens every anniversary. (p 5)
Just wanting to mark them,
wanting to mark a particular anniversary.
My friends bought the bench for C, well, it was C's 21st
And they got together and bought a bench for C,
Which was placed in *Gardens.
And then P and I bought a Magnolia tree and had the tree dedicated to her
ad some Rhododendrons.
And the Rhododendrons were placed round because
when C was little with all her friends,
that is where we used to go to play hide and seek.
So it was all connected really. (p 6)



I played golf and I played tennis, I still play tennis.
I got involved with the school fundraising and got involved with helping the school.
So really the only thing I suppose I think I have done and love to do
is anything that will just help children I suppose.

So you are helping quite a lot of people really. (p 10)

I have made a lot of friends, lots of schoolteachers
And a couple have become personal friends.
So, I suppose part of my life is the bereavement centre,
and the other part of my life is the children,
and I have a social life, so that's the good part about it.

And I think because of the work they do there (bereavement centre)
you can have connections with people which I had never really thought of before.

Yes, probably you have just made me realise that yes,
I have made more friends and acquaintances because
I am more open to listening to people
and to letting people in re me.
It is letting people into your life a little bit more than perhaps I used to. (p 11)

Creativity

Elizabeth used writing to express her feelings and thoughts.
The first piece of writing was written sitting in her daughter's room in the year of her death. It was her way of trying to explain to friends and family "this is how I feel." She said, "I built walls, I know I build walls".

Although I find it very difficult to talk
I want you to know this is not because I don't trust your love for me .

I want to say
 "I don't seem to be able to find peace of mind
 In sleep I do
 In sleep I am closer to C
 But sleep doesn't come easy
 How can I say how much I hurt
 Hurt is in my heart
 At the moment I feel that never before has anyone person felt so much pain
 But, also I know there have been people before
 And there will be people after me
 My feelings are very selfish
 In my heart I know she was P's child too
 She was my parents' and his parents' grandchild
 Please don't think I don't know the hurt and pain they are also feeling
 But in my grief I am an individual
 My grief is personal to me
 And at the time of writing this
 I am only expressing my won feelings
 I say my feelings are selfish feelings because every day I ask God
 Why!
 And I ask him to send her back to me
 Then I get confused because should I ask for her back
 Knowing she was so ill
 The answer of course is always YES
 I just want her back to hold to talk with
 I want her BACK

 The tears just flow
 I think of something
 See something
 Hear a song
 I still have to respect other people's feelings
 but its not always convenient for me to talk
 and then the moment has passed

 I have no incentive to do anything or go anywhere
 I want more than anything to just stay here in C's room
 Surrounded by her things
 I could throw away the key and stay and maybe
 C would come for me
 It's a futile thought
 However I've realised I'm not frightened of death
 It's the only time I've given it a thought
 But at this pint it would come as a relief
 In more rational moments I know I am blessed
 With good family and friends
 Who're sticking by m e no matter how many walls I build up
 And I appreciate all of them

But please try and read this – for me
C was contentment of my life
I loved her company
Now I feel no quality or contentment in my life
I have always been lucky enough to see the beauty of life
Now I can't write about it,
Photograph it
Or listen to music
Will it ever return

I hurt like hell and just sometimes
Someone gets the wrong end of my tongue
I would never intentionally hurt anyone
I'm sorry
Stay with me

The second piece was also written during the first year after her daughter's death, and is appendix (NUMBER)

Thoughts about self, and future (Existential).

I have no fear now of death.
I had never needed to think about death.
I have no fear of death, no, absolutely nothing at all.
In fact I think I am one of the lucky ones
because I believe that now I will see C again.
Never ever thought about that in the past but I believe now I will see her and if I don't,
which people say "what if you don't?"
well by then I'll be dead so it won't make any difference.
And I don't mean that to sound flippant but that's as basic as it gets.
I do believe I will meet C again and I do trust that,
but if I don't it is not going to make any difference. (p 8)

How do you continue your relationship with your child who has died

There are things that will always probably be there
and things that I will always do.
Yes, as a connection.
There is a cup presented at C's speech day every year,
in memory of C, and so I am invited to that, and I still go there.
We don't stop talking about her, even though there are two other children
in my life now. They know all about her,
and they talk about her and that's good. (p 6)
I have always said that C is here with me anyway,
She's never left me.

I wasn't a person who would think like that.

So, it has changed what you understand, a sort of spiritual connection?

Oh yes, definitely. I mean everything I do she is till here.

Do you communicate with her, I am hearing you say that somehow there is a communication.

Yes I think there is.

I think that she actually makes sure that I am doing the right thing,
and maybe there is something,
there is a connection that makes me believe what I am doing is right,
because it is what she would want me to do.

There's something, I don't know what it is, but there is something.
I suppose, again I feel that sometimes I think that I am leading my life in the way that
she would want me to lead my life.
And I am wanting her to be proud of me.

So you feel she is actually alongside you.

Yes. Well, yes, I do know she is with me.
I suppose it is difficult for me because previous to C dying,
I never really knew anyone who had lost a child,
so you don't get into talking about things like that.
And I wasn't really very spiritual,
In my mind, if I am honest, I do everything in C's name.
Anything I do, I do for her. (p 8)

Growth

I suppose I am at the bereavement centre because of C and because
I just want people to know that you can lose a child
and you just don't think you are ever going to get over it,
and I don't want them to say "I want to be like Elizabeth"
but basically, I want them to see that you can have another life.
And that's what I've found.
I've found another life, but C is still part of that life. (p 6)

Things are different.
I think I have learned and I have realised that you can grow,
you can move on, it's not the life we planned....

You know I am contented with my life here,
I know C would be proud of me, which makes me rather content.
And just is practical, everyday things,
I am very content looking after two children who probably should have been

and would have been grandchildren.
And I am of the age
and she would have been the age
where she would have probably been married
and would have had children
and they would have been my grandchildren,
and it's like I was sort of knocked out of the norm by circumstances,
but brought back into the norm by default almost.
But by doing something about it.

What brings you joy now? Do you see the world in a different way perhaps?

I think just the children.
Just doing. Probably giving,
I don't want this to sound sanctimonious;
inside me it's like giving two children who didn't have a chance, a chance.
When my daughter who had every chance didn't get that chance.
So I have handed it onto to other children and that's really all it is.
I don't want it to sound sanctimonious because it isn't like that.

*It doesn't sound sanctimonious, it sounds beautiful. It sounds really meaningful to you.
It's very special what you are describing.*

Well, it is now. They are my life now. (p 7)
And I honestly believe that probably that was what was meant to happen in the end,
I don't know? Because I am not a religious person or a person who says "oh yes, because
of this...." I just now think that somebody, whether it was C or whatever,
somebody led us to this.

*So, it sounds like through C's life and death has come
another stage of your life that is so meaningful. (p 8)*

I am aware that became quite painful for you at one point. Did it surprise you?

Yes that surprised me, yes it did.
I think, because although,
I knew then before when I said,
I am twenty years down the line,
I am making like a statement
"I am twenty years down the line, you can't touch me".
And suddenly it did.
So, it can always touch me can't it?
And I suppose I know it can.
Because sometimes if I do something on C's birthday I know that touches me but
there's only me there then.

So for you what was hard today was that you were with me when that came to you.

Yes, it feels ok that is has though because basically it's like touching base,
it happened, and don't ever think it's easy,
because it's not.

It doesn't go away

It doesn't go away does it?
Because there again,
if that's base there,
then I just touched it again.

And you know what it feels like.

I know what it feels like. (p 9)

Concluding the interview

I probably give more of me now than I ever did.
Maybe that is what it is.
Maybe I need to show people than you can really get through these things.
Whatever life throws at you,
and you don't know when you've not had anything thrown at you.
And when you do, it's a biggie, that you can actually come through it.

*It's almost as if you are really wanting to show others,
And yourself maybe, that actually this is survivable.*

Well, probably, don't sit in a corner.

And my life continues with sadness and joy?

Oh yes, bittersweet really.
Basically the bitter; you lose a child to suddenly find
You life has been enriched by loads of new people,
Two new children,
Obviously your family,
And they're all still surrounding me.

It is a great revelation that twenty years down the line
I am helping to organise the tenth anniversary of the help line.
Things like that, they move you on.
I didn't believe that I could be organising something like this.
I am very shy,
and to do some of the things I have done has amazed me.
I am happy that I can say to people that I have found a quality of life
That I didn't believe would ever be possible and
I am contented with that life. (p 12)

Helen's Story

"I am not broke, I am cracked.
A cracked cup can still serve a purpose,
it's not destroyed."

Beginning the story

C was in the British Army.
He was eighteen, that's all he had ever wanted to do
it was his dream.
On the sixth week of him being down there we were invited for the day out.
So, my husband and myself and my two daughters drove down.
He was the baby.

And your only son.

And my only son.
I suddenly realised he was a man,
and he had gone from being the baby.
So, I was totally gobsmacked that I was looking at a young man
who was able to wash his own socks.

And be independent.

Yes. Anyway, he had a passing out parade, and we went,
the whole family went down.
Beautiful, fabulous day.
He was able to come home with us for three days and then he went back.
And he was posted over to Germany. (p 1)

And in May 1992,
I had woke up in the night,
and I couldn't get him out of my head.

The phone rang
"I am colonel A, and I am phoning from the British Military hospital"
it's weird, I can remember every single word,
"I am afraid to tell you your son has been listed VSIL"

P was going off to Belgium in the afternoon and I phoned his office
and I said "C is very ill and they are coming to get me now."
And I remember grabbing a carrier bag and just throwing things in.

Just had to go

And standing on the front with my passport and this carrier bag and a taxi pulled up.
(p 2)

And I was put on a plane and I don't know where I was going
until the captain said Hanover.

So we got into this massive, oh God, the hospital here has nothing
on the size of this place.

And they took me right along this corridor to intensive care,
and I walked in and C was on this bed in the middle of the room with just a sheet over
him and there were noises of air and hissing and all sorts of strange noises.
And I sat on a chair, and he opened his eyes and he said, "thank God you are here mum."
And fell back asleep.

And then this colonel A, he was Maltese, and he came in and he said I had to prepare
myself that my son wasn't going to live through the night.
And I remember the funny looks, everyone was giving me funny looks. Because I knew
C wasn't going to die, I really knew,
and that's not fantasy, I knew he wasn't going to die.

A real knowing

And he didn't die,
and the next day there was a young nurse, well, not a nurse said to me,
"how did you know C wasn't going to die?"
and I said
"because I knew that he would take every bit of my strength and he would take it and he
would get better."
And I really believe that he did take the strength from me and he used it." (p 3)

That you were willing him to be OK that night.

And then they moved him out of intensive care and put him into special care. (p 4)

And he said to me this day "I wish I could get up."
And I said, "well, get up" and he said, "well they are telling me I cant"
and I said "well, I am telling you you can."
And he said "Mum, it doesn't work that way"
and I said "egh, I am your mum. It doesn't matter about these people, when you're with
me I'm in charge. Not your captains and your colonels."
So, I got him to stand up, and he held on to this pole,
which had three or four different things going into it.
And I opened the door and we went out and the most marvellous thing....
He started, very, very, very slowly.
And he took about ten steps and it was a huge, long corridor with doors off it.
And each time we went a bit further people were coming out of these doors,
They started clapping. (p 4)

My niece was getting married on the last day of May,
and they flew me home. C was walking about, dreadfully thin. (p 5)

And he (Colonel A) said,
“You do realise that this illness is going to claim your son’s life?”
So, I said “yes.”
And then you get that awkward silence,
when they don’t know what to say. (p 5)

I knew that C was coming home. But, he couldn’t fly,
he had to have a medical escort overland.
We had to pick him up at * between twelve and one, the wedding was at three.

And we pulled up outside the church...
P was already in there, and we walked down,
And I remember P turning round to look at him and.....
this.....
terrible, terrible look come over him.
P had his hand on his shoulder, and I thought, I felt good about that and I understood,
even though I didn’t understand a great deal, I understood that P needed to touch him,
to have contact with him,
because it was the first time he had seen him.
And then he went back for further treatment and then he come home,
then he went back, and he come home.

And then P said “I have booked for the three of us to go to Ibiza for a fortnight.”
So, we went on the Sunday and I did not have anything to do with C at all for the two
weeks. They snorkelled, they sat together, they sat and talked,
they swam. I was patted on the head. “Here’s your book, we are going down to the
beach.” I was happy with that. I took a back seat. (p 7)

You knew they needed it?

Yes, yes. And then he went back and then he phoned me on 28th August.
He was backwards and forwards for treatment.
He phoned me up and said “I have got to come home.
They have told me I can’t stay in the army.”
And I said, “You can still stay in the army, get a desk job or something”. And he said,
“No I want to be in the proper army, I don’t want to leave.”

And I got a phone call about nine o’clock,
I could hear all this singing,
and voices and piano music,
I said, “Hello, hello, is that you C?”
And he said, “Yes, I am out having a drink.”
“It’s ok, I am with a sergeant and he wants to talk to you.”

and he said, “ a few officers have taken your son out for a few drinks, hope you don’t mind.”

And I said “no”, but I got a funny feeling come over me.

And he said, “we are looking after him and we are having a good time.”

I said, “Put C back on please.”

And I said, “Are you OK?” and he said, “I am fine mum and I love you.”

And what had happened was, he had argued and argued,
he had persecuted them, and he didn’t want to leave the army
and so they actually told him.

And I think it hurt quite a bit that he was eighteen,
a couple of weeks short of being nineteen,
he was on his own, he had no family with him,
he was in a foreign country, to be told that it wasn’t an option,
he had to go, he was dying.

So, he hadn’t known at that point that he was dying.

And I don’t know what his reaction was and I never will do.
But I know that his officers took him out and he died the next day at twelve thirty.
On the Saturday.

So sudden.

It was, and I think he so wanted to stay in the army, that bad,
I think he must have thought “I’ll have had my last day here and die here.”
And that was it.

It was like he gave up.

I think he did. I don’t think he actually wanted to leave the army and he died.

So, even though you knew he was ill, this came out of nowhere.

No, no.

You knew? (p 8)

By the time I got home, I knew.
I didn’t know when,
and I was hoping that I might have got four or five years.
And the biggest regret
that I never told another living soul.
I didn’t tell my husband, I didn’t tell my two
I said, “He is not going to get any better.”
It was never ever spoke.

So, the fact that you didn't tell anyone else that he had cancer do you mean?

I never told a soul.

*In a way you didn't tell yourself either, because you were saying that you wanted him to
live and you wanted him to continue with life.*

I don't think I was actually telling myself,
because I knew he was going to die,
but I didn't think it was going to be that quick.
I didn't want anyone else in this entire world to feel the same as me.

You were protecting everybody.

Yes. I couldn't have coped with them hurting and I couldn't have took that on board, so I
found it easier just to keep it to myself.

*What a huge thing for you to carry though on your own,
and yet it sounds as though that was what you wanted to do.*

I needed to do it, I didn't want it any other way. I regret that I didn't tell his dad. (p 9)

How grief affected/affects your day-to-day life

Helen described her stages of grief as:

Black, dismal – acceptance – trying to learn to live with it – ok with this – fun now

I put myself in a hole.
And I didn't like the hole,
but I felt OK in there. And I got to like it. (p 9)

I never felt comfortable, I never felt calm,
I never felt peace, I never felt safe,
but if I was on my own, I did. (p 10)

I continually played this one record.
It is called "My son". Have you ever heard it?
An Irish singer called Brendan Shine.
When C was accepted into the army,
I took him into the lounge, nobody every goes in there,
and I sat him down, put this record on and said to him,
"I want you to listen to this record because everything in life I ever want to say to you,
listen to what the words say."

And it's "my son you are the seed of life in me, I can't believe the man I see"
and it goes on.

And he listened to it and he said, "OK."

And I said, "Did you hear, everything I want to say to you, that's it in a nutshell."
"You're my life, you are going away for the first time, remember I always love you."
He said, "I know that mum." Come to look for the record, he had taken it with him.

That's how special it was to him.

He took it with him.

I would play it and replay it, replay it continually all the time.
Cried, lump in my throat. (p 10)

I went back into the room and shut the door.

I wasn't regressing, I just didn't want anyone bloody well near me.
I was like in a dream-like trance, I was drifting through, if I needed a drink, I would go
downstairs, straight into the kitchen, get a drink, straight back upstairs.

How long was this going on for then after C died?

About the March after. I didn't have any connections with anyone. (p 11)

P said "tell me about Germany".

So, I told him little bits, And I told him different things,
and to be honest with you Gail, I was talking about me rather than C to P.

You were telling him what your journey had been?

Yes, how I'd run away, how I thought he was dead, it was all me.

And I was just staring ahead.

Different things would come into my head and I was telling him.

And I turned to him and was meaning to say something along the lines of "I bet that
makes you feel a hundred times worse?" and I looked at him, and he was crying. And I
thought "oh, my God." No, "oh, here we go again".

I just put my arms around his head and the two of us were crying.
And I don't know how long we cried, but I know that we were sweaty, we were
saturated, and we kept this (sobbing sound) for hours and hours together.

For the first time together.

*So, for you, you had had this huge period of isolation with all that you had had to cope
with, with C's illness. And this was the first time, and it was by him actually shaking you
almost, that you then let him in, and you out in a way? Is that what you did?*

Yes, I did. Yes. I come out of the hole. (p 12)

Relationships with family members, friends and colleagues

I was told I couldn't stay there on my own, I needed somebody out there with me,
and as much as I idolise my husband and I know he idolises me,
I didn't want him there.

I
really didn't want him there at all. So, I asked for my mother.

Do you know what that was about for you?

I do now, I didn't at the time,
I just knew I didn't want P there. I didn't want P to feel how I felt.

So, you were protecting him

Yes, I couldn't cope with him having to deal with it.
I really didn't want anyone there,
they wanted somebody else there with me.
I said to my mother, I would have preferred one of my sisters.
I have three sisters and I would have preferred one of three sisters.

*So, you didn't want to protect somebody else and you didn't want to have to worry about
anybody else? If you had to have anybody it was just somebody who could be there.*

And it was silly, I should have just said, "No, I want to be on my own." (p 5)

I didn't need anyone, I didn't want anyone.
I couldn't be bothered with people. I couldn't cope with their stupid looks,
the stupid sounds that come out of people's mouths. (p 9)

So, you withdrew, is that what you are saying?

Yes. I didn't want to look at my daughters,
I couldn't handle their hurt and I definitely couldn't handle P's.

*You had all on to cope with what you were feeling about C
and you couldn't take any more on.*

No, nothing. I pushed everything behind me. (p 10)

He come down the stairs and went towards the front door and I said "no, don't go."
And he said, "Look, I can't go on like this. I can't live like this."
He said, "those girls have gone" which they did,
to live with my mother,

and he said, "you're like a ghost Helen, you float past me." (p 11)

My daughters then come home about four days later.

They were walking round on eggshells with me and I kept thinking "they are so frightened of me" and I sat them down and said, "don't be frightened of me". And they said, "we're not frightened of you mum, we are just frightened of saying the wrong thing." And I said to the eldest daughter "tell me how you feel?"

And she said, "the hardest part was looking at you and people were in the house
And you weren't aware they were there, and what we went through. (p 13)

What helped?

P, P, all the way down the line it was P.

I love the bereavement centre.

Creativity

Letter written February 1993 after C had died in August 1992

I wrote it down.

I am in a deep dark hole,

I didn't fall in,

I put myself in.

I don't like it in here,

But I don't want to come out.

Nobody can touch me or approach me

with a silly look and the daft "ahh!"

I won't look at my husband's vacant eyes
or the deep hurt in my two daughters eyes.

Further down I go,

yes, I do like it,

you see I don't belong to anyone,

I don't need anyone,

I will always feel like this.

If I look up I see the heads against the light.

Just go away.

I wish they could understand.

I want to wallow in the pain, darkness and loneliness.

I hear the whispers

“she is depressed.”
Hah! I wish that was I had,
medication would help me if I was.
I want my son back,
Can anyone help me?
NO!

Thoughts about self, and future (Existential, spiritual)

I am less tolerant of somebody who moans
about having a sore bunion or woe is me.
I think that I have seen a young man in the most terrible pain and I think,
“oh, get a life.”
I am less tolerant of people say over the age of 55, probably 60, who have died.
I can just see the difference between all the bereaved parents who have lost a child,
and somebody who has had a life.
I look on the fact that they’ve known what it is to be married,
they know what the joy is to see their own child born,
to play around with their grandchildren, they have had a life. (p 15)

Yes, I love the bereavement centre.
I look at people coming through the door,
probably the odd time they are helped through the door,
and I know that in whatever space of time there is going to be
they will walk through the door with their head up.

And I think I listen more.
I am aware of what people are saying, even though they are not saying things.

So, you really tune in now more.

Yes, I love walking now.
Really love walking,
love walking in the wind.
I love destroying my shoes and kicking all the leaves in the autumn.

So, you love the earth, the weather.

I would be up, showered, sod the breakfast dishes,
out the door, in the car and go to the woods, and walk.
And I am not thinking of anything, not thinking of C.
Even if I am driving down the road, do you know,
in the start of spring and you see all them daffs.
I have never been a flower person, I have never been a tree person.
When I am driving down and I look at them, I am aware now of the world.
Nature as well by the sound of it.

I notice things more.
I said, we were out * and we had gone for a meal,
P passed a comment about this young girl.
And I said, "I think she looks lovely."
just look P, stand and look at these kids, wearing orange and pink and lilac".

It sounds like you really celebrate, life and beauty and fun.

And I enjoy watching the young kids having a good time,
putting these daft frocks and I think,
"they look lovely, they are bright and enjoying life"
and I could sit and watch them walk past me and thoroughly enjoy it.

I can see something nice in everything. (p 16-17)

How do you continue your relationship with your child who died?

It is C's room.
It's not a mausoleum.
It has been decorated, different floor, different bed, different furniture.
It's still C's room.
It's like, you know when you do a pile of washing that has to go upstairs?
I'll say, "take that upstairs" "where do you want it?"
"In C's room."

So, something about still wanting to be able to say his name, still having a part of the house that you can still connect with him. Albeit it is not a mausoleum, it has changed but it keeps his name alive?

Yes. That's right. It's a part of our way of life, it is used.
Hundreds of people have slept in there but it is still C's room.

I still play the record, and very, very, very occasionally I have a tear in my eye.
But, I enjoy playing it now its ok to cry, its ok,
and I look forward sometimes to playing it.
So, I play that, and I can smile
P doesn't like it, P has his own record that he plays it's "Beautiful boy" John Lennon's
"Beautiful boy". (p 13)

Yes, one of the biggest things of losing a child that I find, is that after a period of time they are never mentioned, never.

By other people?

Yes, you can go a month, six weeks, two months, three months down the line.

And someone will say something like
 "I saw John, C's friend, the other day in town"
 and he's mentioned, but it's few and far between.
 So, if I feel that that's happening,
 I will instigate a conversation, mainly with P.
 And I will start it off, like on holiday.
 "Do you think C would have been married P?"
 And he'll go "probably, good looking lad, yes."
 "And what about grandchildren?"
 And we can talk about that, what if, I wonder if.
 And nice. (p 14)

Growth

I'm comfortable now.
 When I listen to people (other bereaved parents), which I do quite a lot,
 and they say, "Oh my God Helen, how long is this going to go on for?"
 And I said to this particular lady
 "a few years down the line you are going to welcome this hurt,
 because when you get to the stage where you are OK with it,
 and you do get a bad day, it's nice.
 They are still there,
 they can still hurt you,
 you can still feel the love."

*I am thinking you have verbalised something that I suppose I have always known.
 Actually that is really important. It's actually saying that on days when I have a really
 strong connection with my grief and have that gut wrenching pain, I think "Oh thank
 goodness for that."*

Those words don't come into your head, but you actually feel OK with it because they
 haven't gone.

It still matters.

They haven't disappeared.

*So the pain is almost like your connection with your child because of the loss of them?
 Because you can't be with them anymore.*

Yes. That's right.

I hope I never get to the stage where he is fully forgotten.
 I don't want that to happen, so I do enjoy the bad days.
 I also talk to his photograph. (p 14-15)

Kate's Story

"At any moment you can scratch the surface and the grief is there."

Beginning the story

I have three children and C was my eldest.
I worked and my husband worked.
And money was quite tight,
but we had an exceptional family life.
We had a really happy family life.

C went to * University and S went to * University.
D went to high school, she wanted to be a medical secretary and that suited her,
she wanted to stay at home.
The house was always full of people,
because they brought them home.
And C followed * football club,
and if there was a match on,
half the uni would come with him, down to *.
And I would probably make something like beefburgers and onions and they would grab
them on the way and go to the match and then come back.

So, your home was like a hub for everybody.

Yes, the house was always, even as they were growing up,
full of people, children,
and it was a house that was very much full of laughter.
And we didn't realise really until after C died,
that we had everything.
we had no money,
But we had everything. (p 1)

And my daughter was now into football
and wanted to go and watch the match up in *.
She had been to a home match but never been to an away match.
I spoke to my son five times on the Friday
could I get him a ticket for T to go to the match, because she hadn't got one. (p 2)

It wasn't like a normal semi-final match or anything like that,
the queues were horrendous and the road was blocked.
And they joined the queue but more people joined the back.
By the time they got to the main gets, which was like a bottleneck,
and you saw it on television,
my daughter was getting slightly crushed outside the gates
and C was quite agitated for her and trying to protect her.

But, then the next thing that happened was that all the perimeter gates got opened and that was when they went in. (p 3)

And out of the corner of her eye (D),
she said she could see C and he was by a barrier.
And then the pressure got so great on her that she thought she was losing consciousness.

So, how she got out, nobody knows,
but she was nowhere near the gate,
couldn't climb over because there were fences all around,
so nobody really knows how she got out.
But, she sat there and she was one of the first out,
watching the scenes around her.
And she never moved.
Saying because, in her words, "if I stay here, he'll find me." (p 3)

She actually phoned home and said she couldn't find him and P and I drove,
he was in work, and we drove to *,
and we were there quite early, as you would.
And they were all in a club and my daughter had quite a lot of support from C's friends
who my son had rung from London and asked him to get out and go and look for her.
So, there was a lot of that going on,
and it wasn't until quarter past two in the morning
that we identified two dead bodies. (p 4)

Yes. So, we went and stayed in this vicar's house,
and there was a doctor there, who gave us a tablet each,
because after identifying two bodies, we were made
to give statements to the police and we had to stay there and give three statements. One
for G, one for C and an overall statement.
And then we go on from there, and then we went to the vicar's house in which to get an
hour or twos sleep.

Because you were exhausted.

Because it was three o'clock and somebody had given us a sleeping tablet.
So we all took one and we ended up all sleeping in the one bed. For about two hours.
(p 4)

And the next morning we got up and went to C and G's flat.
There was loads of his uni friends there and quite a few people
even though it was five o'clock in the morning, there were quite a lot of people.
And the vicar came in the room with us and he said, as I was crying a lot,
"can't you feel the love in the room from these two people?"
and "god's good, isn't god good" and "you must reflect on god because.."

Are you angry for him saying that?

So, I started to swim,
and I started to swim out there and there was just my husband in there.
And I went quite a long way out, and all of a sudden there was this voice beside me
saying "where do you think you're going?"
And he knew, he knew.
So, all the first year there was nothing positive. (p 6)

One of the longest inquests in history when you hardly hear your son's name mentioned.
And that took up, say six months of your life really.
Because I did that every day.
I was there nearly every day.
And angry really, and there was a lot of anger then. (p 10)

I wanted to know everything,
I wanted to know. (p 11)

You wanted to make sense of everything, as hard as that is.

Yes, I had to find out.
But that consumed my time really and I found out that C,
if he had been resuscitated and put in the recovery position,
probably wouldn't have died.

I had to know about G.
I absolutely adored G, she was everything I could ever want in a daughter-in-law.
She called me ** and I was her best friend.
But when she died I realised that I never told her I loved her.
I told my son every day,
when I spoke to him on the phone the last thing I would say,
we would all say D, S, "I love you babes".
Never any regrets,
he knew how much I loved him, but I had never said it to her.
And I am like that with all my friends, when I meet them,
when they come to the house and I put my arms around them and I would say
"I love you babes."

Because you were worried that you might not get the chance to say it again.

Yes (p 11)

They say that anger is not good,
but in some forms anger is better than the place where I was in wanting to die
and wanting to be with him. (p 13)

Relationships with family members, friends and colleagues

But you also cut your husband out of it

Cut everybody out.

Because he kept saying to me “don’t shut me out.”
But it didn’t matter to me,
he was here wasn’t he?

He’d manage, he’d survive

And these two children were determined that they would protect me.
And I wasn’t even aware that they were around. (p 5)

My daughter is brilliant,
she is my best friend
and she is very strong. (p 6)

But, I still wasn’t taking much notice of my husband or family.
S by this time, seeing that we were getting on our feet eighteen months after,
started to have panic attacks himself.

D, who I hadn’t even looked at in eighteen months
and who I had hardly been aware of, I looked at her one day and I thought “you are
sleeping with your boyfriend”.
And it was a massive, massive wake up call.

*Something about you noticed your daughter and you noticed your son for the first time in
eighteen months.*

Yes, and that was a wake up call.

Because you wanted to be back with them again in a way? You’d missed them?

Yes. (p 7)

I just needed, well my friends had been forgotten,
I never picked up on my friends.
There were a few of them that soldiered on and rang up regardless and came,
you know and God love them they had to put up with some sugar off me.
But they were fantastic, but the rest went by the wayside.
They weren’t even friends, were they? (p 9)
My husband had gone back to work.
He seemed to me to be coping very well.
He wasn’t, when we finally talked about it,
he wasn’t coping very well at all
but I’d hear him whistling when he was cleaning the car,

and I'd think he didn't care, he didn't care, you know? (p 9)

And I also missed the closeness I had with my husband.
Even we were not possibly sleeping together.
Because how could you do something that gave you so much enjoyment
when there is so much sadness in your life.
So, to me, if I did, I'd end up crying my eyes out.
But, again, he was very patient, and very good,
and I suppose he was the same anyway, but we just didn't discuss it.
But things were by no means normal, and we are talking two years now. (p 10)

Memories and images

What helped?

We did television interviews and I was involved with a bloke called **
and he did the story about * and did several papers on it.
He was a great supporter of me.
And I became involved with ** who wrote the drama documentary.

You became involved in telling your story and the story of your son as well.

And why I was telling that story.
I looked through statements from police and I looked through statements of fans
and while I was doing that I was quite strong
because I thought there was a purpose to it.
Purpose to that while as I said detrimental to everyone else around me.
And I had to do it for C.

I decided that I wanted to pack in my job.

So, you made a huge life-changing decision.

I just thought that I couldn't carry on the way that I was carrying on and that I needed to
find something which would give me an inner peace.

Something that would fit?

Yes, I had to change my lifestyle,
I had to change the people I worked with,
I had to come away from people who I thought had no conception of life at all.
Working in an office and they were all arguing about pencils and pens
and it was all so petty,
but it was an everyday thing to me beforehand.

But, this was different now, you were seeing the world differently now.

And people in the office said I was very morose.
I overheard that. I thought, "yes I am.
It's true what they say, I am morose."
But, then
"swap places and let's see what you'd be like." (p 8)

...and I did a lot of walking. (p 10)

Creativity

Thoughts about self, and future (Existential, spiritual)

And then life is just passing me by
and I am going walking now to try to find some kind of peace in my life.

So, for you, walking was what you started to do.

That was the very first thing I started to do, I started to walk.
And I thought, "I have got to find me,
I have got to find somebody I can live with. (p 6)

And I don't want this person who is crying all the time."
And who couldn't even speak his name without cracking.
And spending lots of time at the cemetery,
and I'd also gone from being full-time to part-time.
Because I told the boss I wanted more time to find me.

Nothing mattered really. But, I used to walk the feet off myself,
and I found that through walking I was fine.
Whether it was because I was absolutely knackered, I don't know,
but I was finding that when I went out my shoulders were up by my ears,
and when I come home I was in a more relaxed state.
And I was by this time, it was well over a year, eighteen months, I was beginning to go
into the family circle again.

*So, something about you needed to go and find Kate again,
before you could actually go back and meet the family again?*

Yes, yes.
And the people in work who I worked for wanted me to be the person I was before.

But you couldn't do that any more.

But that person had gone.
The very idea of me going for a booze up with a gang of women,
for a meal, was absolutely appalling.
So, if anybody said to me,

I'd say
"I'll be alright, I just need to find some level in which I can be at peace with me."

So, something about finding a level you could feel comfortable with, given the change?

Yes. That I could live with. (p 7)
I remember sitting down with M who was a really good friend,
and I said to her "M, I have got to find me"
and she said "what do you mean by you?"
And I said "I have got to find somebody who fits into our family life because I don't." (p 9)

And I did pack in work
and I started to go with a friend to spiritualists and faith healers and go to these halls,
thinking to myself "well, if I find out where C is, I'll find out where I am."
But, it didn't work, it just wasted money. (p 9)

. I went looking for spiritual healing and I went listening to what they said. (p 10)

How do you continue your relationship with your child who died?

And I kept saying that to myself
"come on Kate, get a grip, he wouldn't want you to be like this,
he would say
"get on with your life, I can't live mine, get on with yours.""
And I could hear that.

Everything connects, I did a vigil and I could hear him saying in my head
"I always knew she'd be there."

Well, when I go away on holiday,
I always find a cathedral,
I always light a candle and talk to him in the church when I go.
I never was religious, but he is there with me on my holiday.
And I ask him "well you have been here before so what do you think of this?"

So you continue talking to him.

Yes, and I bring him a present back,
sometimes wind chimes for the cemetery, or something on those lines.
Because the others get a gift, he gets a gift.

Do you do the same at Christmas as well?

Oh yes, Christmas time he gets something stupid, maybe a little teddy.
Because Christmas time was always a very fun time in our house and in one of my
bags, the Christmas before he died,
he wrapped up in masses of paper, a snowman about that big,
and it had white fur all over it and these black eyes. And this was just one of the
presents he brought me, stupid presents.
And I carry that snowman everywhere (p 15)

Growth

Instead of wanting to kill myself,
I have got to try and find a level which I can live with.

*And I wonder if we do need to go to that place, and most people if you are brave enough,
and I do think you are being really brave here to say that. I think that most people will
say they have come to a place where they have to make a decision live or die.*

I think you do, it is something which you wouldn't say at the time
"I am just searching for something"
but on looking back on it,
mine was quite conscious really, I thought,
I have got to be around for my children,
I have got to be this person that I was before, for them.
My life's never going to be the same,
but I wanted the relationship back that I had with them.
I also wanted the laughter back in my life, but I couldn't get that.
And I don't know when that even came,
I think that came with my first grandchild actually.
Those belly laughs that you used to have with your children because of the antics of
them in the garden with the hose or something.
Those magic times, you know?
They are quite hard to find again afterwards.
And they do happen, in time they will happen,
but when you are looking for them they never happen. (p 10)

So, your grandson coming seven years later

And he still is, he's adorable. And he is the light of my life. (p 14)

So, you have got real joy from having him.

Oh, he's wonderful.
I say, he made the sunshine again for me.

He made me laugh, he made me be like I was with the children.
Like I was with D, C and S. Be the clown that I was.

So, it was all very much a jokey household that we lived in, and I wanted that back.

It sounds like you have reconnected with that part, through your grandson.

Oh yes. He's lovely

I obviously needed the grandchildren back in my life.
I needed children in my life.

And it sounds like you needed a part of you back as well.

I did. I did. And I have got that back actually,
I have got that back. I mean, I have got all my grandchildren and I absolutely adore them
for everything (p 15).

If anything really upsets me, I have to say,
whether it is right or wrong.
I am quite placid now.

I never was anything else but placid and I would never deliberately upset somebody,
but if something or I think something is wrong I do feel strongly,
I have to say it now.

So, you are more assertive.

I am more assertive about what I believe in if I think, not petty things (p 18-19)

My grandchildren give me my lift.
We go away quite a bit. I like travel, that gives me a lift as well.
The family, last years Christmas gave me a lift,
Yes, so all of that, my grandchildren have brought back to me,
what it was like being like before C died.
The niceness of children,
the good part of having children.
I mean people don't realise.
And again, I am aware of that, people not treating children as they should.
If I see that, that upsets me really bad,
"you don't know how lucky you are."

*So, you come back to valuing the preciousness of children and it has brought back a
sense of your own fun again.*

That's right, that's right.

They have been like a key that has unlocked that part of you.

They did, they do, and I think they will.

Yes, they have brought me back.

Pulled it all together, and not taken away the huge loss you have had with C and not denying that, it's actually saying "and there's this too".

Nobody can ever take away your loss,
nobody can ever take away your grief,
and it will be with you 'til the day you die. (p 19-20)

Janet's Story

Beginning the story

We had waited eight years before we had any children.

Getting pregnant for me was very easy,

It was keeping hold of them that was the problem.

And four weeks before the due date they said

“we are going to have to bring him now”

because my body couldn't take any more.

And it was a very traumatic birth.

He nearly died, I nearly died. (pg 1)

And then at six weeks old he literally stopped breathing.

And we just shot to the hospital.

Anyway, they said he'd got Fallows Dytrology, which is like a hole in the heart,

But also he had Pulmonary Stenosis, which is the narrowing of the arteries.

She said “we will have to operate on him”.

And then they start telling you all these different things and what they are going to do,

but they might as well have said

“Mickey Mouse has come in”

because you don't take it in.

You are in shock

You are just like sitting there going “well what does all this mean?”

I said, “could he die from this?”

And she said, “he could do, but it's very rare.”

And so I said, “OK”

I thought that if he is going to have a short life,

we want it to be as normal as possible.

And in the December we went for his normal routine check up.

He was just coming up to twelve months, and they said he'd deteriorated quite a bit.

He was quite a chatty little thing,

and he was quite an alert child. He was very big, as you can see

(points to his photograph on the wall)

he wasn't a tiny little scrap of a child. (pg 2)

He was due to go in for his operation on 26th March.

So, we went in on 24th, which was the Tuesday,

and then he had it on the Thursday, 26th March.

But, in the night time of 25th we couldn't really sleep.

Because we were just in a chair at the side of the cot.

There was nowhere to sleep.

They took him down and it was horrendous, absolutely awful.

He went down at one,
and at seven o'clock he hadn't come back. (p 3)
So, the next thing is the surgeon came in,
"he is gravely ill,
we've nearly lost him three times".

We were like "Oh, my God!" you know?
But he said "he is still alive but the next twenty four hours are crucial".
So, we thought, "what do we tell our parents?"
So, he said "all you can say is he is very ill".

They had given us this waiting area as our own space,
and I looked up, and I saw, I can't describe it but it's just like this brightness,
this complete bright light and C was sitting there on the floor,
like he was just sitting on a floor. (p 4)

I can't say it was a carpet,
I'd like to say it was a pristine, beautiful, but it wasn't.
It was just like on a floor.

And he got up and he started walking.
Though he didn't walk, because of his condition,
because he used to go blue the minute he walked.
And I shouted "no"
and ran to the intensive care unit and when I looked they were shocking him,
then they brought him back.

About eleven o'clock they brought the doctor,
And they sat the whole family down and they said
"he's turned a corner, he's going to be ok."
So my mum and dad go home and P's mum and dad and his sister, and everyone goes
home. And I wouldn't budge you see, and I wouldn't go.

Anyway, we were just getting up to go, just literally getting up to go and the alarms
started going off.

And they told us if he goes into Tachycardia, there was nothing they could do.

.And then just after one o'clock he died. They were trying, because his kidneys, he had
kidney failure and liver failure (p 5)

and in the end my husband said "stop, that is enough."
And he said "no, that's enough, can't take any more now.
There's nothing you can do, just stop."

And they stopped.
And I said, "I want everything off him,
I want everything off him and I just want to hold him, let him die with me."
So we did that and we sat.

And that was about one.
I think the death certificate says twenty past one.

So you had that time without all that machinery on.

Yes, but do you know what, once I had got him I couldn't cope.
I couldn't sit there.
And now I think, like years later, I really beat myself up about it
because I thought "I should have sat there,
what kind of mother was I?
I should have been sitting there longer with him."

You were terrified

Do you know when you hear people saying
"I sat there while they went cold?"
I couldn't do it you see.

And I couldn't with my son either.

I was scared. Do you know?

*It was the most terrifying experience for me too,
it was something I couldn't do either.
And afterwards like you feeling, shame almost.
I am his mother I should be able to do this.*

It's weird isn't it?
Yes, yes, and going back to the chapel of rest, I couldn't do that either.
And when they said "do you want to see him?"
And if only they said at first, well I know now, now I know why,
but I didn't at the time.

I am glad I didn't see him really.

So you can hold the memory you had, even though that was traumatic.

Even though it was scary, and I don't know why,
and I know it sounds really strange,
but I had never seen a dead body probably before.

*And that's something that bereaved parents will say,
to face death and to face the first death and it is your child. It's just incredible.*

And you don't know what to do, do you? Because nobody tells you what to do. (p 6)

How grief affected/affects your day to day life

I was so strong and stayed together. I don't know how?
Because you've got to basically I think.
And I remember coming home with the car seat in the back of the car.
Thinking "what do we do now?"
And all these people in the city,
you know what it is like,
and your driving through,
and they are all stood at bus stops
and I wanted to stop at the bus stop and say
"why are you waiting for a bus? My son's just died!"
It was the most surreal, oh, I don't know, totally, totally weird.

I had my second child, all I can remember doing was replacing C straight away,
and saying to my husband "we've got to have another one".

I tried to replace him straight away.
There was no question about it, I needed another baby to hold.
I just knew that was what I needed.
Because I had nothing then. (p 7)

I drove round with no insurance and no tax, just wanting to be stopped.
Because I was angry.

You actually wanted to challenge somebody and be stopped?

Yes, yes! I just wanted to be stopped. "Stop me, I've got no tax, I've got no insurance"
It was like I had so much anger that I couldn't express it

Memory loss

I don't know quite what triggered the memory loss
All's I knew it was September.
I remember coming out of the hospital.
And I remember getting to the car and I don't remember anything after that.
I can't tell you any emotions I felt after that,
I don't remember...

So maybe at that time your grief was so overwhelming?

I think I just shut down, like you said. (p 11)

When do you remember getting your memory back, when S was about two?

I think over the three years it is coming back gradually.
Because I have asked people things, to tell me things.
Because I was very embarrassed about it at first and I thought
“oh I am going mad, I must actually be going mad.”

Because in 1999, when we found out about the organ retention you see

That as well

That was there as well,
it was really sort of...
even then I didn't know I had lost my memory.
Even then.

It was like you had to shut down to survive

Maybe, yes. Maybe that is what I did. (p 12)

Memories and images

We put C's chair in the loft
And we put a few things in the loft and we went for tea.
And when we came back the chair was in the living room.
It was here, on the floor here, when we came home.
And my husband, when you're dead you're dead.
Doesn't believe in anything, doesn't want to go there with anything at all like that.

And you had both been together putting it in the loft

Putting it in the loft together and when we came back it was here.
I mean I can only tell that to you.
I could never tell that to my next-door neighbour or something,
because they would think we were nuts.
or made it up. (p 13)

One day I was going upstairs and I just knew he was in the bedroom.
And I was frightened, I was really scared.
And I sort of looked and I said
“look, I know you are in there but I am not ready, for you to see me. I can't see you.”
Because I think in the beginning I was worried about seeing him how I last saw him,
which is all wired up and all awful.
And I knew he was there.
And smell, you know you get the smell of them,
the touch on your face, his cheek.
When I used to work in the village,
in the winter when I used to walk him up.

I used to pick him up out of the pram,
he'd light up when he saw me,
and I used to put his cheek against mine.
His cheek would be freezing, you know, because they had walked up in the wind.
And I used to get that feeling of the cold cheek against my cheek and the smell.

.So, sometimes when I get the feeling of him,
I get the smell of my grandmother first.
And I know that she's with him.
It's almost like, oh, here, they've come together. They're together.

Has it been a comfort?

It has been a comfort, a great comfort to me, I must admit. (p 14)

Relationships with family and friends

And then four weeks later P went back to work.
He had to. It was because he had to.
Because he would have gone completely round the twist if he didn't.
Three years later he collapsed,
but his way of coping was "four weeks, I am going back to work".
So, I was just left.

*Do you know this is the third time I have heard this. The third interview and the third
time I have heard the mother say this is what my partner did.
Almost like, I got on with my grief straight away and three years later my husband
crashed, and that is what my husband did too.*

Yes, I think working on the help line, that's normal.
Men do this "I'm OK routine" and "I'm holding everything together." (p 7)

I didn't want to know anybody.
I fully hold my hands up, everybody who wanted to be here I couldn't cope with.
I didn't want them near me.

So, this affected your friendships, your relationships?

Everything. Absolutely everything and everyone.
I didn't want my friends around, I didn't want my family,
I didn't want anybody.
All I wanted was to just be with these bereaved people.

What was being with your friends and family like, what was difficult?

It was too hard.
Because I had nieces, because there is six months between my niece and my son C,
so it was all like, it was too much. It was like I couldn't cope with the children.

Friends were trying their best.
And I was like "I can't come near you, I can't see you,
I don't want you here, please don't call again."

Oh, I was awful.
And out of all those people now,
there's probably only about on one hand who's stood there, who's stood by us,
and wouldn't let us go.

What does that mean for you?

Oh, well they are your life friends aren't they?
but I was really horrible, I wasn't nice to be around.

I think also for us, I got pregnant straight away,
and that was another thing I was ashamed of.
You know like people say they couldn't go near,
well we couldn't keep away from each other.
It was almost like we had to have that closeness. (p 9)

But I think we just, we had a purpose, but also we just needed that comfort of each other,
I don't know why.

*So where you actually rejected everyone else
it actually drew you and your husband closer?*

We were very close together yes.
We were very together at the time. (p 10)

What helped

I needed to be with other bereaved parents.
I just knew that I needed to be with somebody else who felt like me.

I started going round the cemetery where he was buried and I'd look for children. And
then I'd get all excited if I saw a child's grave, and I'd stay there for ages.

What did that mean for you?

I'd look first to see whether the grave was tended,
and that that grave was looked after,
so that I knew those people were coming to the grave
and that they had survived.

And that you wouldn't be alone.

Yes. And they'd survived.
Because at the beginning I wanted to kill myself.
But

it felt for you at that point that you didn't want to be alive.

Oh, I didn't want to be here.
It was too hard. It was like "I can't do this".
And I used to go round all these graves and if they had flowers I'd think
"Oh that's it, they're going to come"
and I'd sit there.
And I mean hours, and hours, and hours. (p 8)

*So, that was what you needed at that time when you were in the depths of your grief, you
needed to be understood and the only people who could know were bereaved parents.*

Absolutely
I felt that nobody gave a toss about me really

So, you felt really alone

I felt very alone. (p 11)

Our biggest help was talking to the other parents. Getting involved. If somebody had told
me I would be involved, and certainly my husband, in a group, I'd have said "no, that's
not us at all." (p 14)

Thoughts about self, and future (existential)

My life is far more richer,
far more fulfilled,
I know what's important in my life.

Since he died I have become very much aware of different things.
And like, the twigs there, are from the cemetery.

So you are really connected with nature?

There's a tree where he is buried, and when all the leaves fell of they all fell down and I
gathered them and brought them home. (p 15)

I believe it has given me a level of understanding
and a level of sensitivity that I didn't have prior.
I was a very, not a hard person, I was a very down to earth person.

And I think what it's done, I think,
I suppose it's going to sound stupid?
I believe that I have gone through, what I have gone through for a reason.
That this has happened to us, for a reason.
In a lot of ways people say "I wish it never happened and I wish I could have my son
back."
Half of me doesn't think that.
Half of me thinks, if I didn't have this experience,
I wouldn't be who am, where I am now. (p 16)

How do you continue your relationship with your child who died

Keeping his memory alive was very important to me.
Keeping talking about him a lot.
I find it very easy to talk about him.
I mean, don't get me wrong, you have your times when there some things that you know,
a record will come on or something and suddenly it gets you. (p 14)
But what was important for me was that when S was born,
he knew who he was.
S's routine as a baby, we used to have a little egg shaped thing with C's picture in it,
would be getting him ready for bed and kissing C's photograph.
Kiss goodnight, and it was always goodnight to his brother.

Christmas cards, if we go on holiday, postcard, will have the four names on.
We don't have a problem with that at all.

And how do you keep connected with C, you said the garden is one thing.

Well, I started to find that flowers,
I started to have this interest in flowers.
But, something that my mum said I always did when I was little,
but I never knew I had done it, you know.
She said, "when you were little you always wanted to smell the flowers,
you always wanted to look at flowers."
And I started to do flowers on the cemetery, and rearranging things.
And just by chance, these trees we planted got a little bit bigger and I said,
"let's bring them home and plant them, let's not throw them away."
And the garden was just lawn there.
And then gradually we just started bringing everything home, that had grown.
And we found that when we put it in the garden, it just flourished.
And so we started planting things purposely to bring home, so that it would grow.



So, that was almost connecting C's grave with your house?

I have been quite creative that way with flowers and trees and things because,

I feel as if it's living, it's life, it's hard to explain.

It's like a connection with him, it flourishes because it's part of him.

It's because of him.

It's because of him.



Yes, it's because of him that these things survive.
And in that tree, you know, you've got two sunflowers.
We never planted sunflower seeds.
No, we never planted them.
When he died, the first thing that somebody gave me was a sunflower.
To put on the cemetery.

So, it's symbolic?

Yes.



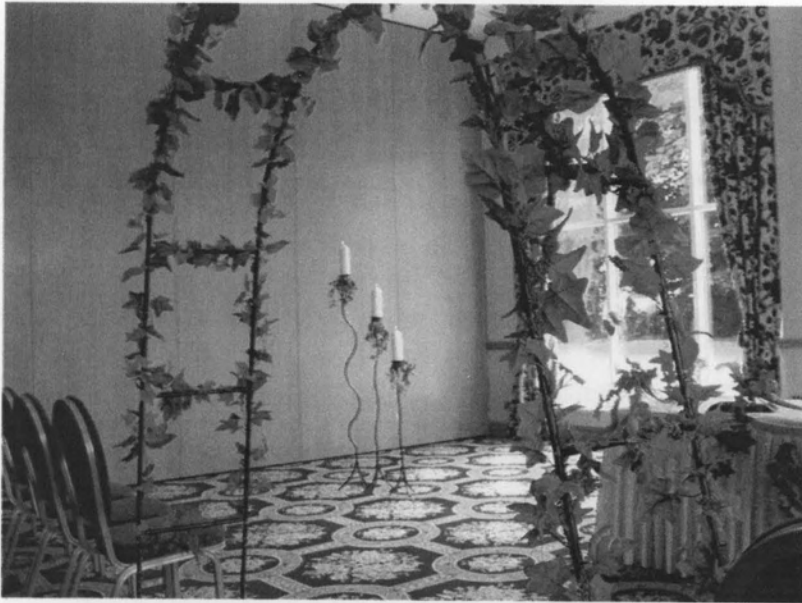
Do flowers mean things to you? Are they symbolic?

Yes, they are all, things like, when my sister-in-law was getting married, for instance,
she was very much aware
that she wanted to include people who hadn't been there.

No matter what people tell you,
you have always got that big hole.
So, I said "right, we will represent them, in flowers."
Because that's my way of representing, in flowers.
So those things on that photograph, there, are representative of that. Nobody knew. The
lilies, her theme was the lilies.

So, the lilies were representative of the people who couldn't be there?

Those three candles were the representative of the people,
and we lit those just before she came up the aisle.
And they were lit right the way through.



Creativity

So, for you then, you continue your bond with C through flowers

Through flowers, through creativity really.

But you didn't do this before C, it was new.

Never would I have said in a million years that I could do that.

I like things that are very symbolic.
 Like, for instance, when they thanked me,
 they presented me with a bouquet of flowers,
 but they bought me that little boy on a rocking horse.
 When it was his birthday or he should have started school,
 or anything my mum bought us a piece of Nao
 So, I have got a piece of Nao for every different time. (p 15-16)

Growth

Because of C,
 he has given me the strength to look at the positives out of it and ignore the negatives.
 But, I don't think that's me, that's him working with me.
 I believe he works with me.
 He's here, oh yes. He's never gone away.
 Never ever left me. I always like to think he is with his brother as well

I find I have got a better level of understanding with people,
because I try to get to the level, where previously I couldn't before.

So, do you really connect with people now?

Well, I think so. People say that about me a lot.

So, do you find that your capacity for joy and fun as well is there as well as the sadness?

Yes, it's like I have just got a different dimension to my life. (p 17)

I wish, probably, that I could have two sons,
like you, healthy children who grew up and we didn't have to experience this.

But, I am not going to let that destroy me,
the fact that that didn't happen to us. (p 17)